THE REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY
(NORTHERN IRELAND)

A Strategic Framework for Adult Mental Health Services

June 2005

CONTENTS

FOREWORD

In the summer of 2002, I was invited to chair this independent Review, commencing in October that year. Shortly after this Professor Roy McClelland was appointed Deputy Chair. It took about 6 months to clarify our terms of reference, guiding principles, high-level objectives, strategic framework and even our title, which became "The Review of Mental Health and Learning Disability (Northern Ireland)". By March 2003 it was clear that the work consisted of several interlinked reviews under one overarching title, and encompassing policy, services and legislation.

The Review Steering Committee presides over the work of 10 major Expert Working Committees. Four Committees commenced their work by April 2003, and a further 6 by November 2003. In consultation with Government, we agreed to produce our reports separately in a phased manner. All of our Committees have adopted an evidence-based approach, drawing upon existing relevant information and research, and where necessary commissioning research. Exemplars of best practice local, national and international, have informed our Reports.

We have maintained a clear vision for mental health and learning disability services in Northern Ireland. Widespread consultations with stakeholders have endorsed our vision and the strategic direction of the Review. A feature of the Review process is the contribution of Users and Carers across both Mental Health and Learning Disability. Their insights, advice and guidance continue to be invaluable. The recommendations for service reform have been underpinned by a sound economic appraisal carried out by our Needs and Resources Committee. As recent research by the Northern Ireland Association for Mental Health has shown, the cost of mental health needs of the people of Northern Ireland are considerable and extend well beyond the direct cost of health and social care.

This first report from the Review set out a vision for adult mental health services for the next 15 to 20 years. The sucess of this depends on the contribution of stakeholders, but most of all, Government, who must give a lead in implementing the process of change. We fully recognise the resource implications and urge Government, in particular the Department of Health, Social Services and Public Safety, to begin the necessary process of reform and modernisation of these services as quickly as possible.

I thank all involved in this Review for their efforts. An immense amount of work is in progress.

DAVID R BAMFORD (PROFESSOR)
CHAIRMAN
June 2005

INTRODUCTION

BACKGROUND

1. A Review of the policy, practice and legislation relating to mental health and learning disability was commissioned by the Department of Health, Social Services and Public Safety (DHSSPS) in October 2002. The main factors influencing the decision to establish the Review were:

   - recent reviews of mental health legislation in neighbouring jurisdictions;
   - the need to ensure that law, policy and practice is in keeping with human rights and equality law; and
   - the need to reflect current evidence of best practice.

HUMAN RIGHTS AND EQUALITY PRINCIPLES

2. Everyone has human rights and must be valued for his/her self-worth. Moreover, States and international organisations have a duty to uphold and protect these rights.

3. However, since people live in social settings, the human rights of any individual have to be considered in the context of relevant and often competing rights and interests, for example, the right not to have one's liberty restrained carries with it a potentially opposing right of another individual not to be endangered.

4. Human rights, including the rights of people with disabilities or mental disorder, should not be arbitrarily diminished. There are circumstances when it may be appropriate to curtail a person's human rights, but this should be limited to the minimum extent necessary, and a person whose rights have been curtailed should be entitled to appropriate care and treatment.

5. Those who deliver health and social care must uphold these human rights and equality duties in performing their functions. Ultimately, law and decision-makers, including members of this Review, have to strike the appropriate balance in relation to the relevant rights and interests.

6. Rights are useless unless people enjoy the protection offered by human rights in their daily lives. It is crucial that people know about their rights and, where these appear to have been breached, are able to enforce their rights.

7. To enable people with a mental health problem or a learning disability to exercise the same rights as others, additional support, information and training

may be required to maximise understanding and participation. Ensuring equality of opportunity can also mean making structural changes, tackling discrimination and addressing the assumptions and attitudes of others about learning disability or mental health.

8. Putting human rights and equality principles at the centre of the law, policy and delivery of these services under review is a legislative imperative because of international and domestic law. These principles also need to be taken into account in professional codes of conduct and practice.

9. The principles on which the Mental Health (Northern Ireland) Order 1986 should be interpreted are contained in the relevant Code of Practice 1992. These include reference to:

- dignity;
- individual background;
- resources;
- least degree of control and segregation commensurate with individual safety and the safety of others;
- lease restrictive alternative; and
- treatment and care that promotes self-determination and responsibility.

10. While the clearest outworking of this Review's deliberations on human rights and equality issues will be seen in future reports from the Social Justice and Citizenship and Legal Issues Committees, human rights and equality considerations are reflected in all of the Review's work, including this report.

STRUCTURE OF REVIEW

Steering Committee

11. To oversee the Review, a Steering Committee was established under the chairmanship of Professor David Bamford. The Committee has representation from a wide range of professional interests, the voluntary sector and from service users and their carers. Three members come from neighbouring jurisdictions.

12. Details on the Committee membership are at Annex 1. The Terms of Reference agreed by the Committee are at Annex 2.

Expert Working Committees

13. Work on specific aspects of the Review has been delegated to 10 Expert Working Committees, which were established in two phases during 2003. Brief details on these are at Annex 3.

14. Conscious that the workforce is a key resource, the Steering Committee has been collaborating with DHSSPS on a workforce planning group on mental health and learning disability services under the chairmanship of Mr David Bingham, Director of Human Resources in that Department. The Steering Committee is anxious to see not just an increase in the numbers of staff working in the mental health and learning disability fields, but also that these staff are equipped with the appropriate skills for the models of service delivery envisaged in the future.

15. The Steering Committee decided that reports would be made to Government in stages, as the work of the Committees was completed. This report represents the first major report from the Review, and deals with adult mental health services across primary, community and hospital sectors. Other reports will follow over the next 12 months.

VALUES AND PRINCIPLES

16. One of the Steering Committee's first tasks was to agree a set of values and principles to underpin its work. Key among these are:

- Involvement and Open Access;
- Inclusivity;
- Quality;
- Existing Excellence; and
- Research and Information.

The Views of Stakeholders

17. At the outset of the Review, Professor Bamford wrote to over 200 stakeholder organisations in the statutory and voluntary sector, seeking their views on priority areas which the Review should examine. A series of meetings with stakeholders was held and a policy of open access to the Review and its work has been maintained. The comments received from both written responses and the stakeholders meetings have informed the work of the Committees.

18. Working Committees are also engaging with stakeholders as their work progresses. The Review operates an open access policy, in that any individual or organisation can present their views to the Steering Committee or any of the Working Committees.

19. A website has been established to keep stakeholders and the general public informed on progress and with the work of the Review (www .rmhldni.gov.uk).

Service Users and Carers

20. The views of service users, carers and families are central to the Review . The Steering Committee and Working Committees have user and carer representation within their membership.

21. User and carer reference groups have been established in respect of both mental health and learning disability services. Each of these groups has a membership of about 15-20 people. With their help, consultation events have been held in various locations to allow a wide range of people to voice their opinions and tell their experiences. A freephone message line (0800 3284260) was also established to enable service users and carers to make their views known, in an anonymous way, if they wished.

The Evidence Base

22. One of the principles informing the Review is that it should be grounded on the best available evidence base. As part of defining the quality and appropriateness of evidence, due consideration has been given to relevance, applicability, reliability and validity. While noting these various dimensions, for the Review as a whole the following classification has been adopted:

(A) An expert user group or carer group opinion;

(D) Descriptive surveys of client groups; Evaluation of client needs and services; Systematic user surveys;

(N) Interventions studies – non – randomised trials;

(R) At least one randomised controlled trial; and

(S) Systematic reviews including at least one randomised controlled trial.

23. It should be noted that the optimal evidence for particular issues may be quite different, for example, descriptive analysis for community mental health morbidity. The various dimensions of evidence need to be considered with the emphasis on fitness for purpose. That said, the adequacy of the evidence base

in a number of areas is still relatively weak and the Review emphasises the importance of strengthening this with new research and service evaluation initiatives.

The Adult Mental Health Expert Working Committee

24. This Committee first met in February 2003. Details on its membership are at Annex 4. While this portion of the Review focuses on adult mental health, several areas of adult services are the subject of separate reviews – Forensic Services, Alcohol and Substance Misuse, Dementia and Mental Health Issues of Older Adults.

Structure of the Strategic Framework for Adult Mental Health

25. The report recognises and follows the natural division of our Health and Social Services into Community and Primary Care (Chapter 3) and Secondary Care (Chapters 4, 5 and 6). It also considers the requirement for regional level services because of the expertise required for people with particular mental health needs (eg people with eating disorders) (Chapter 6). While general consideration of the nature and size of mental health problems is considered in Chapter 2, the particular epidemiology of the disorders considered in Chapter 6 and Annex 6 are, for convenience, considered alongside the service considerations and recommendations for each of these groups.

Interface Issues

26. The Strategic Framework for Adult Mental Health is part of a review of the whole system of provision for people with mental health problems and people with learning disability embracing services, policy and legislation. The Strategic Framework, therefore, must be seen in the context of the entire Review. The success of any reform of adult mental health services is dependent upon the successful reform of the system as a whole. There are many interfaces between adult mental health services and other services. This Strategic Framework reflects these interfaces and, where appropriate, gives detailed consideration to them. That said, because of the phasing of the work of the Review, there may be issues in the interface areas which are identified subsequent to the drafting of the Strategic Framework and may need to be incorporated. Services in several areas outwith adult mental health have historically been less well developed, notably child and adolescent services, forensic services and specialist services within adult mental health.

27. While the emphasis of the Strategic Framework is the service needs of people with mental health problems, a holistic approach to the issues of mental ill-health also requires a robust strategy for prevention and mental health promotion. Issues surrounding secondary prevention and the needs of families and carers have been considered core to the service reform proposals within this Strategic Framework. The broader requirements of a strategy for mental health promotion are the subject of a separate report.

28. The Review includes reform of legislation driven by principles and priorities underpinning policy and service reform. This we believe is the right way round. Nevertheless, the review of mental health legislation is likely to have an impact on service development and provision. Again, as with other interface issues, the Strategic Framework for Adult Mental Health will need to consider the impact of legislative reform on service requirements.

USER REFERENCE GROUP STATEMENT

As Experts by Experience we are key to the Review . We claim our right to be valued for our diversity and dignity and to shape the community and practice of mental health care. Everyone has mental health needs and anyone might have need of services. In an imperfect world people become emotionally stressed, depressed and unwell and can benefit from help and healing. Mental health services need to be delivered in terms of needs and rights.

For the New Vision to be achievable the values and principles must be upheld and implemented. Legislation must follow these values and principles.

Each of us in the Experts by Experience Group has our story of the negative effect of the conditions and provisions of care. One element must be changed and that is the attitudes of the professionals and all those who engage with us. Essential to empowerment and recovery is a person centred approach. Understanding the person on their own terms and placing them at the centre of the process.

When the cause of the 'crisis' is commonly social and emotional, clinical responses are often inappropriate and ineffective. What is needed are respect, understanding, and the provision of a safe and welcoming environment. Hospitals do not often provide these responses. Home or respite service responses should be the norm.

As Experts by Experience we recommend crisis responses from a variety of sources that include service user and carer initiatives and participation. The person in crisis must have a choice of care.

Responses to people with mental health problems have been driven by an ethos of doing to rather than being with, resulting in service users become objects to control, maintain and rehabilitate. We are deeply concerned that treatments which are controversial, invasive and which can be fatal are still in use. Within this environment, individual recovery can never be fully realised.

Empowerment and recovery must replace older notions of rehabilitation. Mental health workers will encourage and support persons on their own journey of recovery. The role of the mental health worker should be augmented by the advocate, in particular the peer-advocate, to aid communication, create an equal and positive relationship between the mental health worker(s) and the person.

The community has a critical responsibility towards the recovery of the person, providing sanctuary in times of crisis and alternatives to acute hospital care. The community must support networks for the person, allowing them to affect their recovery with support from peers, their families and friends.

Service users must be involved with real consideration of the positive contribution they can make to the mental health services. We are invaluable in the planning, development, delivery and monitoring of services.

Our experience of services gives us a unique insight into:

- Self: only you can know yourself
- Others: an appreciation of others in distress
- Service provision: what works and what does not work
- Other statutory and voluntary agencies and how problematic they can be for the individual.

Service user-led initiatives provide a safe, confidential and supportive environment and must be resourced and supported.

The expertise of people who have experienced mental health problems must be recognised equally with research based evidence or practice evidence. Evidence-based research needs to include social, psychological and environmental investigations. They must be valued and promoted equally with pharmaceutically funded research.

Mental health service users' skills must be incorporated within professional training and education.

Service users must be involved in the recruitment of mental health personnel and in continued assessment of all professional development.

A STATEMENT PREPARED BY THE CARERS' REFERENCE GROUP

We in the Carers' Reference Group all have family members or close friends who have had experience of the mental health services and therefore have a deep and personal interest in, and a significant contribution to make to the development of services relevant to mental health and learning disability. We fully endorse the statement submitted by the Service User Reference Group.

We welcome the current Review and the opportunity to be involved in its work. As carers we wish to assert, and with enthusiasm and commitment implement, our right to active participation in the Review and in subsequent planning, monitoring and development of public services which intimately affect our lives and the lives of those for whom we care. As is the case with service users, carers need to be involved at all levels, from individual assessments and care planning to reviews of government policy in community care.

Consultation with, and involvement of service users and carers in policy making which affects their lives is a legal requisite, especially under Section 75 of the Northern Ireland Act 1998. Good practice is assessed in terms of how well such consultation and involvement is carried out, and the relationships and improvements in policy making and implementation that develop from it.

We endorse government policy concerning the need for partnership between civil society and statutory authorities as the basis of effective change and express our willingness as carers to become actively involved in partnerships across and within sectors.

We support a human rights, equality, and needs-based approach to the development of policies and delivery of services, and a commitment to providing the necessary resources for the implementation of the Review's recommendations.

A model of recovery and empowerment, rather than traditional paternalistic notions of rehabilitation, is strongly endorsed by the Carers' Group as the way forward in the maintenance of good mental health. The nature of support should be person-centred and holistic, recognising and utilising the fact of social existence as the essence of humanity and well-being.

We acknowledge complex and sensitive relationship issues that can arise with mental health service users and their families, including that of confidentiality: that they can be successfully dealt with. Carers have an enormous, often unacknowledged, contribution to make in being part of a community of support for those they love and care for.

In the development of care plans carers have a, frequently untapped, wealth of experience and information that can enable the formation of an appropriate support package.

In terms of community care, carers seek acknowledgement and support for their involvement as part of the series of community based networks – circles of friends – that will contribute to the recovery of their family member or friend.

We wish to be part of the creation of a process that makes a real difference to lives. One that is self-reflective and responsive to need, and in which the expertise and experience of the services users and carers is central.

CHAPTER 1

VISION, PRINCIPLES AND POLICY

A NEW VISION FOR ADULT MENTAL HEALTH

1.1 The vision underpinning this Strategic Framework is common to the Review as a whole:

- valuing those of us with mental health needs, including rights to full citizenship, equality of opportunity and self-determination;
- addressing the challenges facing people with mental health needs; and
- a process of reform, renewal and modernisation of services that will make a real and meaningful difference to the lives of people with mental health problems, to their carers and families.

1.2 The vision has been greatly informed by core values derived from the consultations, the submissions to the Review and the direct involvement of users and carers throughout our work. People with mental health needs and their carers should receive services which:

- respect them as individuals – through openness in the providing of information, respect and courtesy in individual interactions with service users, true partnership and empowerment in service planning and provision – with Government, providers and the wider society each accepting their respective responsibilities;
- demonstrate justice and fairness – resources for services should be allocated and managed according to criteria which are transparent and which demonstrate equity.

1.3 These values are underpinned by our obligations as a community under Equality and Human Rights legislation.

PRINCIPLES

1.4 The principles for the Strategic Framework draw on the vision and values of the Review and are as follows:

- partnership with users and carers in the planning, development, evaluation and monitoring of services;
- partnership with users in the individual assessment process and all therapeutic interventions of care and support;

- delivery of high quality, effective therapeutic interventions, care and support;
- equity of access and provision of services, including the needs of people from minority cultures, people with disabilities, people subject to the criminal justice system;
- provision of services which are readily accessible;
- delivery of continuity of care and support for as long as is needed;
- provision of a comprehensive and co-ordinated range of services and accommodation based on individual needs;
- taking account of the needs and views of carers, where appropriate, in relation to assessment, therapeutic interventions, care and support;
- provision of comprehensive and equitable professional and peer advocacy, where required or requested;
- promotion of independence, self-esteem, social interaction and social inclusion through choice of services, facilitation of self management, opportunities for employment and social activities;
- promotion of safety for service users, carers, providers and members of the public;
- provision to staff of the necessary education, training and support; and
- services subject to quality control, informed by the evidence.

1.5 Informed by these values and principles, the Review has provided a unique opportunity to address the full spectrum of issues relating to adult mental ill-health. The Strategic Framework provides the blueprint – a blueprint that is as dependent on a cultural change as much as investment of new resources. This incorporates a new sense of partnership and equality of esteem for service users, a valuing of carers as equal partners in service provision, effective team working and collaboration with and between provider groups including user provided services.

POLICY

Where we have come from

1.6 Over the past 30 years successive local and national strategies and a growing body of research evidence have advocated refocusing of service provision away from hospital settings towards community based provision. This shift reflects the preference of service users for home life over institutional care, for local services over distant ones, for services sensitive to community needs and the pursuit of normalisation and integration. It has led to a strong emphasis on the provision of more and better care in the community, embracing support for primary care services and the development of a spectrum of community facilities and services; the participation of service users and carers as partners in service planning, development, delivery and monitoring.

Where we are

1.7 In its consultation with Boards and Trusts, the Review has been greatly encouraged by the efforts currently being taken to address the present shortcomings in service provision. Planning initiatives have been well-informed by new research evidence and exemplars of service development elsewhere. The voice of users and carers is becoming better organised and they are gradually becoming more involved in the planning and development of services. We are fortunate in having a very committed and professional workforce.

1.8 Within Northern Ireland, considerable development in the provision of community mental health services and care has taken place. Nevertheless, recent reviews by Boards, professional organisations and voluntary organisations,[1] while noting the strengths of present provision, have highlighted deficiencies. For example:

- while Northern Ireland policy has focussed on the development of community mental health service provision, the pace of development has lagged significantly behind developments in England;
- identified deficiencies point to the following service needs:
  - a person-centred approach;
  - more inclusive and integrated services, including better working between primary and secondary care;
  - better community alternatives, particularly in the area of assessments and crisis;
  - better services promoting recovery including greater participation of service users and, where appropriate, their carers;
  - greater availability of psychological therapies;
  - better out-of-hours service provision;
  - a more collaborative and inclusive approach to care planning; and
  - more accessible advocacy, with user and carer involvement.

Where we need to get to

1.9 The goals of this Framework are to:

(i) provide better health outcomes and better outcomes for personal and social functioning for all people with mental health needs;

(ii) ensure effective, accessible and safe services;

(iii) guarantee service users and their carers significantly improved experience of and satisfaction with services; and

(iv) give staff real and meaningful opportunities for professional development and job satisfaction.

1.10 The aim is to ensure that each person with mental health needs receives appropriate services, where and when he/she requires them. The emphasis is on fitness for purpose.

How to get there

1.11 To ensure a balanced and inclusive Strategic Framework, the following high level objectives have been set:

- specific reforms and modernisation of services for people with mental health needs;
- specific models of care and standards of provision in relation to the quality, comprehensiveness, effectiveness, accessibility and acceptability of provision;
- detailed consideration of primary and secondary care services, the interface between services, the linkages and interfaces between health and social care, education, culture, arts and leisure, employment and housing, the complementary roles of statutory and independent services and the issues surrounding multi-disciplinary and multi-agency working.

1.12 Fundamental to the creation of improved services for people with mental health needs are:

Workforce development:

- with an increased supply of health and social care professionals;
- with improvements in the skills and competencies of professional staff;
- with greater development of user and carer led services; and
- with the flexibility to change and to contribute to change.

Information on:

- services, for users and carers;
- the prevalence of mental health morbidity and needs for services; and
- how successfully services meet the needs of people for therapeutic interventions and care.

Sustained interdepartmental support and investment to:

- provide for a substantial increase in a wide range of community services, supports, options and opportunities; and
- improve the quality and accessibility of inpatient provision.

1.13 The Strategic Framework envisages a broad and detailed reform and modernisation of services. Given the complexity of this process, clear signposts to mark out the highway of reform are essential. This is provided by 10 Framework Standards which, in turn, are underpinned by a detailed roadmap for change (Chapters 3, 4, 5 and 6).

1.14 Given the anticipated long-haul nature of the reforms, requiring many years to achieve the Strategic Framework goals, it will be essential that the implementation process is performance-managed. The Standards and their underpinning recommendations, therefore, have been mapped directly onto a set of Performance Indicators (Chapter 8).

THE STANDARDS

1.15 Ten Standards are proposed to give clear direction to the Strategic Framework.

Standard 1. Services to be Person-Centred

1.16
– A person-centered approach to planning and provision, with recovery central to the vision
– A whole systems approach to strategic reform and modernisation
– A planned approach to the whole system of mental health services organisation and development
– Independent providers fully engaged
– User and carer involvement in planning, development, delivery and monitoring
– Good managerial cohesion, information management and team working
– A comprehensive workforce strategy.

(Recommendations 19 – 23)

Standard 2: Effective Community and Primary Care Services

1.17 – Community groups including employers and educational providers promoting the mental well-being of those for whom they have responsibility

- Person-centred planning and a quality assured range of provision at primary care level
- Service user and carer involvement in service development, delivery, monitoring and evaluation of Primary Care Services
- A range of advocacy provision in Primary Care
- Targeted investment in primary care teams
- Seamless arrangements between primary and secondary care settings
- Access to a named mental health professional
- Accessible out of hours services
- Effective arrangements for continued professional development.

(Recommendations 1- 18)

Standard 3. Effective Community Mental Health Services

1.18 – Comprehensive coverage by CMHTs

- CMHTs adequately staffed to a minimum of 50/100,000
- Ready access to a range of community resources including independent and user led provision
- For people with complex and enduring needs:
- User participation in preparation of care plans
- Yearly multi-disciplinary review
- Mental health liaison services for all general hospitals
- Accessible and effective range of evidence-based and up-to-date therapeutic interventions
- Tier 2 services for people with psychological trauma, eating disorder, personality disorder , disorders of gender or sexuality , women with perinatal mental health problems, deaf people with mental health problems.

(Recommendations 24 – 28, 54 – 63)

Standard 4. Effective Crisis Services

1.19 – Comprehensive provision of 24/7 appropriately resourced Home Treatment Services

– A single system of acute and crisis provision including Home Treatment, Day Hospital, Step-up, Step-down and Inpatient services

– All services of high quality providing a range of therapeutic interventions, sensitive to gender and cultural needs

– A lead clinician or manager with overall responsibility for inpatient services.

(Recommendations 29 - 35)

Standard 5. Promoting Recovery

1.20 – Those with greatest need given highest priority

– A comprehensive range of community services available to facilitate recovery of those with complex needs, including appropriately resourced CMHTs, Home Treatment and Assertive Community Treatment Teams

– Separate services for younger people with a first episode of psychosis

– Appropriate provision for people with mild learning disability, service users growing older, people with challenging behaviours, people with mental health problems along with alcohol or substance misuse

– Tier 2 services for adults with acquired brain injury or progressive brain disease, Asperger's Syndrome or high functioning autism.

(Recommendations 36 – 53, 64+65)

Standard 6. Sustaining Meaningful Lives

1.21 – Service users with complex and enduring needs enabled to live fulfilling personal, family and social lives

– Opportunities for education, occupation and leisure

– Choice of a range of accommodation and support

– A readily accessible Social Security system

– Easy access to Advocacy services

– Services sensitive to cultural, religious and spiritual needs.

(Recommendations 66 – 80, 85+86)

Standard 7. Providing for People with Special Needs

1.22 – Specialist regional services in addition to primary and secondary care services for people with eating disorders, acquired brain injury or progressive brain disease, psychological trauma, personality disorder, people with Asperger's Syndrome or high functioning autism, disorders of gender and sexuality, women experiencing mental health problems during the perinatal period and deaf people with mental health needs.

(Recommendations 100 – 136)

Standard 8. Meeting the Information and Support Needs of Service Users, Carers and Families

1.23 – Full implementation of existing policy and legislative obligations relating to users and carers

- Easy access to comprehensive information on services
- Service users and carers provided with appropriate support, education and information
- Family interventions should be an integral part of mental health practice
- Service users who are parents supported in their parenting role
- Where children may require protection, agreed protocols established between young people's services and mental health services.

(Recommendations 81– 84, 87 – 99)

Standard 9. Ensuring Sound Information for Mental Health

1.24 – Information systems to support professional staff, service providers and to enable the Department of Health, Social Services and Public Safety to monitor effectively the roll-out of its new Strategic Framework

- A Research and Development Strategy to inform and update the Strategic Framework.

Standard 10. Delivering an Effective, Competent and Confident Workforce

1.25 – A comprehensive regional, flexible workforce strategy to underpin the Strategic Framework, embracing multi-disciplinary workforce training, recruitment, retention;

- Provider workforce strategies which include recruitment, retention, training, support, career opportunities.

1.26 These 10 Standards underpin the detailed recommendations emerging from this Review (Chapters 3, 4, 5 and 6) and map directly onto the Performance Indicators which signpost the delivery of the Strategic Framework (Chapter 8).

A BLUEPRINT FOR CHANGE

1.27 The Strategic Framework provides a blueprint for reform and modernisation of services based on the agreed principles and values. It adopts a strong user and carer perspective and specifies evidence-based service models aimed at addressing the current problems and barriers to good practice (Chapters 3, 4, 5 and 6). It is underpinned by programme recommendations for funding, human resources, information management, research, service evaluation and performance management (Chapters 7 and 8).

CHAPTER 2

THE PRESENT STATE OF MENTAL HEALTH NEEDS AND PROVISION OF SERVICES

INTRODUCTION

2.1 Consistent informal advice and information from service users, carers and service providers emphasise the existence of significant gaps and deficiencies in service provision for people with mental health needs. Strategic planning, to be effective however, must be grounded on detailed population based information on mental health needs. This should include knowledge of:

- the prevalence of people with mental disorder*;
- the nature and prevalence of problems experienced by those suffering from mental disorder; and
- the extent to which current services meet the needs of these people.

Each of these issues is considered in the following sections for mental health problems in general. The prevalence of those disorders for which regional provision are proposed are described along with specific service requirement (Chapter 6).

THE PREVALENCE OF MENTAL ILL-HEALTH

2.2 From a global perspective, the scale of the challenge posed by mental illness has become increasingly clear in recent years. One in ten adults worldwide are affected by mental health problems at any one time, accounting for over 12% of the global burden of disease[1]. Mental health problems account for over 30% of all years lived with disability, and in the developed world account for over 40% of the total burden of disability.

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* Mental disorder is best understood as deriving from an interplay of biological, psychological and social factors. The term mental disorder is used throughout this Review to refer to a range of specific mental illnesses such as schizophrenia, bipolar disorder, depressive disorder. It includes other disorders such as mental health problems arising from neurological disorders for example epilepsy, Parkinson's Disease, brain injury secondary to trauma or substance misuse. These are defined in the International Classification of Disease (version 10).

The term mental health problem is also used in recognition of the fact that, particularly for people with more complex and enduring mental health needs, problems may extend beyond the disorder itself; indeed the primary disorder may be in remission. These problems include difficulties with thinking and decision making, problems with esteem or self confidence, difficulties with social tasks and functions. These are defined within the International Classification of Disabilities and Handicaps.

2.3 Within the United Kingdom (UK) there are significant variations in the level of mental health morbidity. Socio-economic deprivation has a significant impact on prevalence, reflected in, for example, the level of unemployment and the quality of the social environment. The social deprivation experienced by the Northern Ireland community is among the worst in Western Europe.[2] In the period 1997 – 2002, average gross weekly household income in Northern Ireland was only 78% of the UK average. Northern Ireland's unemployment rate has been consistently higher than that of Great Britain, and in 2001 was 6.2%, almost 30% higher than the UK average. In addition, the community has experienced 30 years of civil conflict.

2.4 While social and economic factors contribute significantly to mental well-being the opposite is also true. Around half of the disabled population in the UK are economically inactive compared with only 15% of the non-disabled population. Moreover, people with mental health difficulties have the lowest employment rate of all disabled people (18% compared to 48%).[3] In Northern Ireland more than a third of Incapacity Benefit claimants have a mental or behavioural disorder.[4] In 2002, over 37,000 people were on Incapacity Benefit as a result of mental and behavioural disorders, and just under one in five people receiving Disability Living Allowance (DLA) gave mental health reasons as the main disabling condition.

2.5 Using the General Health Questionnaire, the Northern Ireland Health and Social Well Being Survey (2001) found a prevalence of mental health problems of 24% among women and 17% among men. Such rates are over 20% higher than the rates in England or Scotland.[5]

2.6 While at the present time we do not have an in-depth profile for Northern Ireland as a whole, a detailed prevalence study has been completed for the District of Derry.[6] The 1-year prevalence of psychiatric disorder was over 12%, consisting mostly of depressive and anxiety disorders. The overall prevalence was again greater than the UK average and similar to a deprived inner city area of London.[7] The prevalence of psychotic illness was 0.46%, similar to findings from UK national surveys.

2.7 While this study does not allow one to generalise to the rest of Nothern Ireland, it provides important pointers to the expected general prevalence of disorder elsewhere. In particular, it confirmed clear and strong associations between the level of psychiatric morbidity and poverty.[8]

2.8 Within Northern Ireland there is a significant variation in the level of social deprivation.[9] Among the most deprived are homeless people. A recent study of homelessness in Belfast found that 37% had mental health problems, rising to 41% among single residents in accommodation for homeless people, half of whom had moderate or severe levels of mental health impairment, as well as high levels of unmet need for most services. [10]

2.9 The impact of 30 years of civil conflict on community mental health has been assessed in several community based studies. In a random sample of 1000 adults, Cairns and Mallett[11] found 16% to be "direct" victims and 30% "indirect" victims of civil conflict. Perception of being a victim was consistently associated with poorer psychological well-being.

2.10 Again O'Reilly and Stevenson[12] in a separate household survey found a positive association between the extent to which people and areas were affected by the conflict and significant mental health problems. A variety of evidence, including the findings of these prevalence studies, [8, 11, 12] is revealing that the ceasefires have not been associated with any improvement in mental well-being. The civil conflict has, therefore, cast a long shadow on the mental health of the community in Northern Ireland.

2.11 Suicidal behaviour is one of the major health challenges in Ireland, north and south: a challenge for mental health policy, services and the wider community. A particular problem is the substantial increase in suicide over the past 20 years among younger people. It is now the number one cause of death among 18-24 year olds in Ireland.

2.12 While suicide is a major health challenge, it is the tip of an iceberg. Recent research in Ireland and the UK have found rates among those who would consider committing suicide to be around 20% among young people, with 7% carrying out acts of deliberate self-harm. While the challenge is particularly in the area of primary prevention, the service needs of young people in psychological crises needs to be considered particularly at community and primary care levels.

NEEDS FOR CARE

2.13 Needs can be considered as problems which may benefit from care or treatment. Prevalence of mental ill-health is only an approximate guide to needs, as these are not just determined by symptoms, but from associated features such as impaired social functioning. Many aspects of a person's life may be disrupted as a consequence of a mental disorder. This may include suffering caused by symptoms, loss of independence, lower quality of life and difficulties with social interaction.

2.14 Assessment of population needs is an essential step in the planning of services. A systematic and comprehensive evaluation of mental health needs for care and treatment has not been carried out for Northern Ireland as a whole. However, in the District of Derry study, needs for care were found to be met in less than 30% of care episodes. In a large proportion, needs were not met because people had either not presented or not continued with treatment. This reluctance to engage with services, which has been confirmed in national studies,[13] highlights a need for better public education and information and for services that are more accessible and user-friendly.

2.15 The generally agreed priorities for mental health services highlight the needs of the severely mentally ill. The District of Derry study included recording the number of people with psychotic disorder known to primary, secondary and non-statutory services. This gave a prevalence of 0.46%, consistent with the most recent UK prevalence estimates.[14] Schizophrenia was the most single common diagnosis, present in over half.

2.16 The Medical Research Council Needs Assessment Interview was used to assess psychological and social need. While the most frequent problem areas related directly to illness, (eg psychotic symptoms, the effects of medication), other symptoms (eg anxiety, depression) were relatively common. In addition, a wide range of problems were found in social functioning. The presence of these additional problems must be considered in service provision.

2.17 The wide profile of problems affecting this group of people highlights the need for a holistic approach to service development and delivery. Of equal importance for service planning is the extent to which current services are meeting the needs of this group. While in the above study the most common problem area, psychotic symptoms, was for the most part being dealt with satisfactorily, medication side-effects were being addressed in just over half.

2.18 A substantial amount of unmet need was also identified in the areas of psychological and social functioning, including under-activity, difficulties with day to day activities, where between one third and one quater of all needs were unmet. The issue of unmet need in relation to neurotic symptoms may be important, not only for quality of life, but also in relation to the well-recognised high suicide risk among this group of people. Unmet need was greatest among males and people with longer duration of illness.

2.19 A new Northern Ireland Strategic Framework for mental health must include better information on mental health and better information on service needs.

SERVICE PROVISION

2.20 A third element in the information requirements concerns services, both current and planned, and a matching of these to local population needs. As part of this Review, baseline information is currently being obtained on existing services provided by each Trust throughout the Board areas.

2.21 Mental health inpatient provision in Northern Ireland, as in the rest of Ireland, is and has been significantly greater than in England. Historically this may have reflected greater commitment from local administration in providing for the most vulnerable in our society. However, the present relatively high level of provision reflects a lack of alternative provision, the result of deficiencies in the current and previous strategies, lack of investment and resources. Baseline information recently obtained from service providers for the Review indicates current acute inpatient provision for adults under 65 years to be approximately 50/100,000 adult (<65) population and continuing care inpatient provision for all adults to be 28/100,000 adult population. There is significant variability across Northern Ireland.

2.22 Local evidence points to high levels of need among people with the most severe forms of mental disorder and to significant service gaps, particularly in relation to co-morbid emotional needs and social provision. Services for the severely mentally ill in particular require better community provision and better resourcing of day care and community based interventions, including adequate numbers of appropriately trained staff.

THE ECONOMIC AND SOCIAL COSTS OF MENTAL ILL-HEALTH

2.23 The Health and Personal Social Services expenditure on adult mental health in the year 2002/03 was £110 million, 6.1% of the total expenditureon health and social care. Over half (57%) of the mental health expenditure was on hospital services.

2.24 However the total economic costs of mental illness is much greater than the direct health services costs. For example, the estimated economic effect of depression on employment, and hence on national productivity in cost terms, is over twenty times greater than the costs falling to the health services[15]. In a recent study the Northern Ireland Association for Mental Health, in collaboration with the Sainsbury Centre for Mental Health, London, has estimated that the total financial cost arising from mental ill health in Northern Ireland in 2004 to be £2,852,000,000[16]. This includes the cost of care, loss of output and the human cost. It has been estimated that overall about 70% of the costs of mental illness is borne by the individuals who experience it and their families[17].

2.25 Currently the Northern Ireland expenditure on mental health services is less than the comparator expenditure in England. From the Needs and Effectiveness Evaluation Report the per capita expenditure for 1999/2000 in Northern Ireland was at a similar level to that in England. This, however, takes no account of the characteristics of the populations of the different countries with different levels of need.

2.26 Two significant indicators used in resource allocation formulae are dependence on income support and standardised mortality ratios. Research evidence shows a strong correlation between deprivation and need for adult mental health and social care services. In Northern Ireland the proportion of 16-64 year olds dependent on Income Support is 60% higher than in England. The standardised mortality ratio, a measure of early death and a proxy for morbidity, for 65-74 year olds is 6% higher than in England. The Needs and Effectiveness Report estimated that Northern Ireland's need for mental health services was around 25% higher than in England.

2.27 Since 1999 and with implementation of the National Service Framework for Adult Mental Health in England and Wales there has been a significant investment in mental health services. Expenditure on mental health in 2002/03 accounted for 11.8% of public spending on health and social services compared with 8.4% in Northern Ireland for the same period[17].

CONCLUSIONS

2.28 Present information on mental ill-health needs for treatment, care and service provision, together with economic evaluation, point to the requirement for greater investment in mental health services throughout Northern Ireland.

2.29 A new Northern Ireland Strategic Framework for mental health must include better information on mental illness and better information on service needs.

The evidence base for local practice must be underpinned by greater investment in epidemiological and mental health services research.

2.30 A holistic and comprehensive approach to service provision and mental health practice is necessary to address the high prevalence and the wide spectrum of health, psychological and social needs of people with mental health problems throughout our community.

CHAPTER 3

COMMUNITY AND PRIMARY CARE SERVICES

INTRODUCTION

3.1 A fundamental principle of this Review is that mental health and social care should be provided in the community unless there is good reason for not doing so. Mental health care in the community embraces the spectrum of mental health promotion, pre-primary (community) care through social networks, ill-health prevention, generic care, specific interventions by primary healthcare teams and specialist secondary services. The following key themes provide a rationale and foundation for the development of community (pre-primary) care and primary mental health care:

- The principle of equity must underpin future community and primary care services;
- Much psychological and emotional distress can be resolved by the imaginative use of generic services, the voluntary sector and by community development approaches which provide support to people at times of need;
- Most people with mental health problems who receive health and social care services do so entirely in a primary care setting;
- Service users and their carers prefer primary care based services, which are accessible, responsive, and work in partnership, thus respecting the insight of service users and carers;
- Investment in primary care produces better healthcare outcomes in respect of activity in both primary and secondary care[1];
- Each individual with mental health problems should be given the opportunity to have their mental health needs understood and addressed promptly within primary care settings, taking into account biological, psychological and social dimensions;
- Commissioners of mental health services must carry out comprehensive needs assessments at population and community level; and
- Community and primary mental health care requires systematic efforts being directed towards mental health improvement. This is being examined by a separate Expert Working Committee.

ILL HEALTH PREVENTION

3.2 Mental health service providers can assist other organisations such as employers, educational establishments and community groups to develop specific strategies in time to prevent mental ill-health. Such strategies should be directed towards people who show no overt signs of mental disorder, but who are in high risk groups such as young adult males in socially disadvantaged localities. Much can be done using dedicated support systems and services for vulnerable individuals who show evidence of psychological distress.[2]
Good Practice Example (Annex 5.3.1).

3.3 Early detection of signs of distress may lead to the speedy resolution of the problem. Where the problem is more persistent, then it is essential that people have access to services offering early assessment and early treatment. At these early stages psychological distress does not often fit easily into conventional classifications and should be addressed in a manner and setting which is acceptable and accessible to those suffering. These early interventions have much in common with the public health model described by Albee.[3]
Good Practice Examples (Annex 5.3.2).

3.4 Early prevention and assessment strategies can minimize any stigma associated with traditional mental health models. It is clear that there will always be those who, in spite of the very best system of prevention, will develop more severe or enduring problems.

3.5 Employers have a duty to ensure the mental well-being of their employees. The use of employee assistance and counselling programmes is commended by the Review and should be made more widely available.
Good Practice Example (Annex 5.3.3)

Recommendation

1. Employers, educational establishments and community groups must promote and ensure the mental well-being of those for whom they have responsibility.

3.6 Voluntary agencies play an important role in providing services to people with mental health problems. However, they are often unable to rely on consistent and planned levels of funding from statutory bodies. There are clear opportunities to expand the role of voluntary agencies at primary care level.

Voluntary agencies often have the flexibility to respond innovatively to the changing demands of mental health care.
Good Practice Example (Annex 5.3.4)

3.7 The Review believes that those responsible for assessing mental health needs at community and primary care level must have available a quality assured range of adequately funded, supervised and monitored voluntary services to whom they might refer. In particular ready access should be ensured to self-help and guided self-help through a variety of media including video, audio, written word and electronic storage.

Recommendation

2. Commissioners of mental health services must seek to develop and expand the range of independent services in order to provide a planned and quality-assured profile of care available to service users at primary care level.

USERS AND CARERS INVOLVEMENT

3.8 In spite of much recent progress involving services users and their carers in the planning and delivery of mental health services, there is much left to do.[4] All services providing care for mental health problems should foster a culture where users and carers are actively involved in the planning and delivery of services as well as being fundamental to the monitoring, developing and refinement of services.[5] Service users and their carers have much to offer to programmes of education and initiatives designed to reduce stigma and increase acceptability of mental health services. Carers may have their own mental health needs requiring support and specific interventions.[6]

Recommendation

3. All community and primary care mental health services provided by and commissioned by statutory services must have service users, their carers and families involved in the development, delivery, monitoring and evaluation of services.

ADVOCACY

3.9 At present the use of advocacy in community and primary care is not well-developed. The Review recognises that primary care professionals advocate for service users in secondary services and welcome both formal and informal advocacy within the primary care setting. Advocacy occurs at individual, family, group and service level. Particular problems associated with mental illness might require specific advocacy skills. Advocacy services described in Chapter 5 should be linked to services within primary care.

Recommendation

4.	Community and primary care organisations must ensure that advocacy arrangements are developed within primary care settings.

PERSON-CENTRED PLANNING

3.10 People should be encouraged to take as much control as possible over their own care. A Person-centred Plan could be developed, led by the service user, supported by his or her carers and advocates, in partnership with professionals. This would enable care to be planned in the context of the individual's aspirations and life as a whole. It would also enable service users to make more effective use of direct payments.

Recommendation

5.	Community and primary care organisations should facilitate person-centred planning.

PRIMARY CARE TEAMS

Team Structure

3.11 At present primary care teams in Northern Ireland face many difficulties. They vary in composition and size, and in the skills available within them. A full range of professionals is often not clearly identified, deployed or networked as a team, and there are a number of different management arrangements within teams. These include independent contractors such as General Medical Practitioners, Community Pharmacists; practice employed staff such as Nurses and Receptionists; Trust staff, such as District Nurses, Health Visitors, Community Midwives, Social Workers and aligned staff such as specialist mental health professionals or Allied Health Professionals.

3.12 Quality patient care is dependent on the effective functioning of primary care teams. It is vital that the teams comprise the full complement of professionals and that the varying contractual arrangements and managerial structures do not impede effective team working. A strategy for the development of primary care in Northern Ireland must recognise the obstacles to effective team working. Each practitioner should have a clear knowledge of the roles and responsibilities and when onward referral is appropriate.

Recommendations

6. Membership of the primary care team should be clearly defined and each team should have the full complement of professionals. Organisational barriers should not impede effective multi-disciplinary working.

7. There should be targeted investment in the development of primary care teams to promote better recognition of common mental health problems and clear working arrangements for managing such problems.

WORKING ARRANGEMENTS

3.13 Contractual arrangements for delivery of general medical services offer opportunities to improve mental health care at primary care level. Work is be required to determine how mental health services can best be arranged within the framework of core, additional, extended and enhanced services.

3.14 Local Health and Social Care Groups play a key role in the development of primary care mental health services. Where they become commissioners of services, it will be necessary to ensure that conflicts of interest do not occur within organisations responsible for both commissioning and provision of similar services.

3.15 Contractual arrangements for groups such as Community Pharmacists offer opportunities to reflect the substantial contribution to be made by people throughout the primary care setting.

3.16 Efficient working at primary care level can be dependent on efficiency of working at secondary care level. Mental health care working in Northern Ireland shows that seamless delivery by single management structures provides better services than when several Trusts are involved in delivering care. It is in service users best interest that management boundaries are broken down where possible.

Recommendations

8. Statutory mental health services must have seamless management arrangements between secondary and primary settings in order to maximise the efficiency and effectiveness of service delivery.

9. New working arrangements in primary care should seek to maximise treatment of mental health problems in primary care.

ASSESSMENT

3.17 The fundamental role for primary care is to ensure that individual needs are met in a timely, appropriate and accessible manner. In many cases this can be achieved by members of the primary care team such as Social Workers, offering social care and intervention, Health Visitors and Community Midwives giving advice about the emotional effects of pregnancy and childbirth, Practice Nurses giving lifestyle advice, Community Pharmacists managing concordance and the General Practitioner prescribing for significant depressive illnesses.

3.18 For assessment of more complex needs appropriate expertise must be available at primary care level and appropriate referral to other agencies arranged where necessary. A minority of practices presently have directly attached mental health workers (link workers). Such arrangements have advantages for patients and for the primary care team. It is important however that such workers retain the ethos of team working with colleagues from a mental health background and that adequate professional supervision, clinical guidance and personal support are offered, as well as opportunities for continuing professional development. It is equally important that mental health workers feel part of the primary care team in order to integrate care within primary care services. Identified primary care mental health professionals (link workers) should offer support, advice and guidance within the primary care team. The assessment process should be auditable and should contribute to the continuing education of all involved. Lessons may be learnt from the experience of innovative projects such as in Limavady and Mid Ulster. It will also be appropriate for primary care teams directly to employ mental health workers to provide specific psychological, social or pharmacological interventions. It is envisaged that such workers will be few in number at first (2/100,000 population) but will increase as workforce competencies and funding permit.
Good Practice Examples (Annex 5.3.5)

Recommendations

10. All primary care teams must have access to a named mental health professional (a Link Worker) in order to provide timely, appropriate and accessible assessment and management of people with mental health problems.

11. Mental health services must be accessible in order to provide timely and appropriate assessment and treatment in a manner valued by service users, their carers and by practitioners.

IDENTIFICATION AND ACCESSIBILITY

3.19 Most people with mental illness should be and are treated in the primary care setting. There is a problem of under-recognition of mental health problems by General Practitioners and other members of the primary care team. Present evidence suggests that educational initiatives, whose effectiveness has been measured, have a limited effect, which might only be of short duration. There are many contributory causes to under-recognition of illness including time constraints, characteristics of the practitioner, setting of the consultation and characteristics of the patient.

3.20 It is recognised that issues of stigma can prevent people accessing appropriate mental health care.[7] It is important the primary care teams recognise the internal[8] and external causes of stigma[9] in order to devise working arrangements to facilitate access. Teams should formulate policies of good practice for health promotion, disease prevention, early diagnosis, illness management and referral within and outside the team. Difficulties regarding confidentiality and consent should be addressed specifically.

3.21 One of the key skills of a General Practitioner is to interpret the complex and different range of problems often presented by their patients, to come to an agreed understanding regarding the nature of these problems and then negotiate an appropriate course of action for each problem. General Practitioners have crucial roles to play in managing inter-relationship between physical and mental health problems and ensuring the delivery of holistic healthcare to people.

3.22 Similarly, one of the key skills for Social Workers, working with client groups such as families, people with disabilities and vulnerable adults is to identify psychological and emotional stress and refer on appropriately.

3.23 The uptake of specialist community mental health services is likely to be better where such services are developed locally, are not perceived to be institutional and provide specific interventions as well as offering supportive aspects of care.

3.24 It is known that major psychiatric illnesses such as schizophrenia and affective disorders, carry a significantly increased burden of mortality and morbidity from physical causes. It is essential that primary care structures offer opportunities for assertive recognition and management of risk factors and early management of physical health problems in those with mental illness.

OUT OF HOURS SERVICES – THE NEED FOR MENTAL HEALTH SERVICES NOT CONFINED TO OFFICE HOURS

3.25 Service users and carers value the opportunity to get advice about their problems and about treatment. Crisis assessment and intervention services (see Chapter 4) should be provided for those for whom hospital admission would be the only other alternative. Mental health providers should also however, offer locally-based dedicated telephone advice from qualified staff. Such services might also offer support, advice and arrange appointment for people with services that might be offered during the next or subsequent working days.

3.26 All providers should seek to offer extended hours facilities and services at times convenient for users, rather than those based on office hours that avoid holidays and weekends. Examples include statutory services provided by Trusts and Voluntary sector services.
Good Practice Example (Annex 5.3.6)

3.27 Access to mental health services in an emergency can be through a number of means. Primary care out-of-hours services may overlap with hospital based accident and emergency departments and with dedicated mental health services. The targeting of Crisis Intervention Services to those who would previously have been admitted to hospital leaves a significant number of people who are experiencing significant personal difficulty for example overwhelming social distress, have self-harmed or are acutely intoxicated. It should be clear to service users, carers and to practitioners how best to access appropriate services. Local agreements will be required to define the working relationships between hospital liaison teams, primary care teams and community mental health services.

Recommendation

12. The means of access to out-of-hours mental health services should be stratified according to clinical need and to comprise face-to-face contact, telephone advice and arrangements for organisation of services during subsequent working days.

SCREENING TOOLS

3.28 There is evidence that the use of screening tools in healthcare increases the detection of mental health problems. Commonly used research tools are recognised to run the risk of identifying disorders where none are present. This can cause significant worry to those being screened and divert attention from those with greater needs. There is not evidence to advocate the widespread use of screening tools. The Review encourages their use to support trained practitioners in the assessment of targeted populations at risk or suffering severe mental health problems, such as those admitted to hospital following deliberate self-harm, or those thought to be at risk of developing perinatal psychiatric illness.

3.29 Many practitioners value checklists for common disorders, such as those contained in the World Health Organisation Guide to Mental Health in Primary Care.[10]

Recommendation

13. Formal screening tools should be used to support trained practitioners in a holistic assessment of at risk populations.

PSYCHOSOCIAL CARE, COUNSELLING AND SPECIFIC PSYCHOLOGICAL THERAPIES IN COMMUNITY AND PRIMARY CARE

3.30 There is patchy and inadequate provision of psychological therapies in community and primary care. There is clear evidence that psychological therapies should be routinely considered as an option when considering mental health problems, with particularly strong evidence for patients suffering from addictions, depression, psychosis, anxiety disorder, eating disorders and post traumatic stress symptoms. Specific psychological therapies do not preclude the simultaneous use of medication or social interventions. Indeed such combinations may have a complementary effect for treatment of some presentations.[11]

3.31 It is recommended that a tiered approach to assessment and treatment is utilised (see Chapter 6.4).

3.32 All primary care workers offer a degree of psychological support. In addition some will have specific competencies to provide tier 1 or tier 2 interventions. Mental Health Link Workers should aid other practitioners to secure access to psychological therapies and to more specialised services.

3.33 The evidence for counselling is variable in quality and outcome. The best evidence for efficacy is for structured specific interventions rather than generic counselling[15]. Counselling is not recommended as the main intervention for severe and complex mental health problems or personality disorders. Much support and counselling can be provided by voluntary agencies providing that guaranteed standards are assured.
Good Practice Examples (Annex 5.3.7)

3.34 Much can be achieved by people availing of self-help. This may be through access to written or electronic media, guided self help or by participating in self help groups.

SKILLS AND COMPETENCIES

3.35 All professional staff in the mental health field have a role in providing psychological interventions. This may include psychosocial interventions which are an integral component of routine mental health care and/or specific psychological interventions. The qualifications, training and skills of each practitioner will differ. More complex problems require greater skills. [14] It is essential that anyone delivering psychological treatments has received the minimum level of training that would enable them to carry out therapies safely and effectively. It is also essential that adequate clinical supervision is provided for the work to ensure that it is done safely and effectively. Continuing development of a therapist's skills and supervision is also important if therapy is to be delivered to an acceptable standard. [12]

3.36 Key considerations with regard to psychological therapies are:

- education, training and workforce development for all primary care staff to develop cultures of excellence;
- the use of partnerships between statutory and voluntary sectors, particularly to allow creative use of community resources for those with less severe mental health problems;

- the provision of health promotion and illness prevention programmes targeted at those in at risk groups;
- the need for the service to develop with regard to evidence-based guidelines to practice in order to allow joint decisions between practitioner and service user about care packages; and
- a focus of adequate resources in primary care.

Recommendations

14. People receiving care at primary care level must have access to a high standard of psychosocial care and to a range of psychological therapies delivered by people working in managed clinical teams.

15. All practitioners offering psychological therapies must have assured levels of qualification, experience, supervision and monitoring.

USE OF MEDICATION

3.37 There is clear evidence for the use of antidepressants in moderate or severe depression, for the use of antipsychotic drugs in psychosis, for prescribing mood stabilising agents in bi-polar affective disorder and for the short-term use of anxiolytic agents.

3.38 Perceived problems in Northern Ireland include long term use of benzodiazepines, polypharmacy, failure to offer appropriate treatment to those who need such treatment and use of treatment in those unlikely to benefit from treatment.

3.39 There are opportunities to develop closer working arrangements between prescribers and pharmacists. All people with mental illness, living in the community, who require medication will obtain this through a community pharmacy. The role of the community phamacist is developing. The DHSSPS strategy[13] or pharmacy in the community envisages pharmacies as an open door to the health service providing up-to-date quality focused care. Opportunities exist to extend the existing Medication Management Service to psychiatric medications prescribed within the community.

3.40 Guidelines are available outlining the evidence-base for the use of drugs in the major mental health categories. It is known that guidelines seldom work unless practitioners have been involved in the production and ownership of such guidelines. The Review commends evidence-based guidelines such as those prepared by the British Association of Psychopharmacology[14] and the National Institute of Clinical Excellence.[15]

3.41 Involvement of users and carers in the development of locally-agreed practice guidelines is important. Pharmacists can provide a valuable role in developing treatment protocols. They can also facilitate educational initiatives with primary care staff as well as offering opportunities to patients to have their medication regimens monitored and tailored according to safety, tolerability and efficacy considerations.

3.42 Factors of particular note include:

- antidepressants are a first line treatment for major depression irrespective of environmental factors. Antidepressants are not indicated for initial presentation of acute mild depression. Education, support and problem-solving are indicated. People with minor depression are at risk of developing major depression:
- it is essential that tolerability, safety and efficacy of the prescribed drugs are reviewed regularly:
- particular care should be given in preparing patients for discontinuation of medication:
- the choice of drug treatment should be made jointly by the individual and the clinician responsible for treatment based on an informed discussion of the relative benefits of drugs and their side-effect profile:
- whatever treatments are offered it is essential to engage the service user in a collaborative, trusting and caring relationship at the earliest opportunity:[18]

Recommendation

16. Those responsible for prescribing physical treatments in mental illness must be encouraged, within a multidisciplinary framework, to develop protocols for the prescribing, monitoring and review of treatment regimens according to evidence-based guidelines.

RESEARCH, EDUCATION, DEVELOPMENT AND CLINCIAL AND SOCIAL CARE GOVERNANCE

3.43 There is currently no clear structure in Northern Ireland for the recognition and dissemination of good practice in mental health care.

3.44 There is a clear need to stimulate innovation by directing funding towards research into service delivery and treatment choice in primary care settings.

3.45 The challenge of delivering continuous targeted education is great.[16] There is a constant need for professionals to maintain high levels of knowledge and skills, while fostering developing and sharing examples of best practice.

3.46 The implementation mechanism following this Review must ensure that provider agencies are facilitated in delivering high quality, evidence based, accountable service models.

3.47 There is much that services in Northern Ireland can learn from other local services and by practitioners sharing information within their own services. There are also clear opportunities for fostering teaching and research links both locally and nationally.

Recommendations

17. The Department of Health, Social Services and Public Safety must ensure that there are mechanisms to identify examples of good practice and to encourage widespread implementation of these.

18. Local statutory mental health providers must be funded for, and take responsibility for, the continued professional development of primary and secondary care staff by ensuring targeted and audited learning. The Review commends the use of multidisciplinary models of learning.

CHAPTER 4

SECONDARY MENTAL HEALTH SERVICES – PART I

A PERSON-CENTRED APPROACH

4.1 The Strategic Framework provides a service blueprint for adults with more severe mental health problems and needs* requiring the specialist skills and facilities of mental health services. This includes:

- enhanced support for primary care services;
- a range of services for people with acute needs;
- support and interventions to promote recovery and address the residual effects of mental disorder which can significantly impact on the personal, domestic and occupational aspects of daily life;
- the psychological, educational and training needs and aspirations of service users;
- the management and prevention of relapse; and
- the need for psychoeducational support for family members and carers.

4.2 A person-centred approach to service planning and provision is fundamental. The focus for strategic development is the individual service user and his/her family, person-centered and family-orientated services enabling and empowering the person with mental health needs and their family. Mental health services must reflect the multi-dimensional nature of service user and carer need, embracing:

Health Needs
Occupation
Accommodation
Carer and Family Needs
Education/Training
Income
Personal Life, Family Life and Culture
Advocacy

Recovery must be core to the vision for strategic development of services.

4.3 The Framework envisages a major shift in the centre of gravity of secondary mental health services being achieved over the next 10-15 years. With appropriate development of the full range of community based services it is anticipated that the need for admission to hospital will be much reduced and the duration of admissions much shorter.

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* More severe health problems and needs arise from such mental disorders as schizophrenia, bipolar affective disorders, severe depression

4.4 **Service Planning and Development**. While the sections which follow review each of these issues and associated service requirements, beginning with health needs, consideration must also be given to the whole system of service organisation and delivery. Central to effectiveness of a person-centred holistic approach is the integration of services – the relationships between different service elements and functions require careful planning, including sequencing, appropriate for local arrangements. The optimal shape of local community mental health services should therefore be the subject of careful planning and consultation including the involvement of representative service users and carers. Independent providers must be fully engaged as appropriate, in planning, development and service delivery. Person-centred services must be needs-driven considering both service users and their carers.

4.5 Service configuration should be considered for mental health as a whole (see 4.118). The principles that must inform configuration are that:

- delivery of services are focused on the community and not dealt with separately from other community health and social services;
- service delivery bodies cover a population of sufficient size to allow for delivery of an appropriate range of services;
- resources are equitably allocated according to need;
- transparent accountability for resources exists within each programme of care;
- commissioning of services is based on population groups co-terminous with one or more providers;
- a regional mechanism is used for commissioning and delivering highly specialised services;
- a regional body has responsibility for strategic planning and for monitoring of strategy implementation, service development and delivery;
- administrative boundaries for HPSS Services are aligned with other public services (for example, education, housing);
- the role of the independent sector in the planning and delivery of services is fully recognised;
- partnership arrangements which integrate the independent and statutory sectors are supported.

4.6 A smaller number of delivery bodies than currently exist, covering larger populations, would give each of them more leverage in terms of budget and a better capacity to deliver smaller sub-specialities. Based on consultations, provider units based on an adult population size of 200,000-300,000 is recommended, informed by the Review of Public Administration. A regional mechanism is required for a small number of highly specialist services.

4.7 Inpatient services are an important element in the whole system of care and must be considered in that context, not in isolation. While Northern Ireland still has its six large psychiatric hospital sites, the direction of change throughout the UK, Western Europe and beyond is away from this form of provision. This change has been achieved through development of community care and alternatives to hospital for both acute and longer term care.

4.8 The Review's vision for service development includes a significant acceleration of this process for the people of Northern Ireland. Acute inpatient services should be located within the community they serve and closely integrated with the other service elements, particularly crisis services (see 4.23). For people requiring longer term residential care, this should, as far as possible, be community based. Some service users with persistent and severely challenging behaviour may require prolonged periods of hospital provision (see 4.34, 4.63). The present balance of resource spend is approximately 60% on hospital services and 40% on community services. The recommended developments in community services should be reflected in a reversal of this balance of expenditure within 10 years of implementation of the Strategic Framework.

4.9 For each of the groups with special needs (see Chapter 6) there is a small requirement for highly supported provision, including independent sector provision where appropriate. The needs of adults requiring treatment in conditions of security are considered in the report by the Forensic Services Committee.

4.10 Configuration of services is considered further at paragraph 4.118 following review of the various elements of service provision.

4.11 **The process of change**. The sequencing of planned changes will be most important. In general, investment and development in community based services will be an essential first step to service development, including any restructuring of inpatient services. It is essential that the needs of those within the current model of provision, service users, carers and staff, are addressed as part of the change process. Particular attention must be given to the small number of people still resident in mental hospital settings, many now elderly and frail.

4.12 Adult Mental Health Services cannot be considered in isolation. There are many interfaces between adult services and other services. A key interface is between primary and secondary care (see Chapter 3). Consideration must be given to the transitional needs of younger people, older adults and those with less severe learning disability, in consultation respectively with child and adolescent services, services for older adults and learning disability services. There are also important interfaces with substance misuse and forensic services. The needs of people requiring specialist services (see Chapter 6) must be reviewed by each local service provider in consultation with the Department. While all Trusts should assume responsibility for tier 2 services (see Chapter 6) some must assume responsibility for tier 3 and 4 services.

4.13 The service reforms and developments envisaged for Mental Health Services are considerable. The changes and the process of change will present formidable challenges for professional staff, administrative staff and management at all levels. These challenges must be adequately prepared for. Robust service organisation, information management, team working and communication will all be pivotal in realising and maintaining these reforms.[1] (see 7.7) These must be complemented with a comprehensive workforce strategy embracing recruitment, retention, training, supervision and also the participation of service users.

Recommendations

19. A person-centred approach to service planning and provision must be adopted with recovery core to the vision of strategic development.

20. Strategic reform and modernisation, including service configuration, must be considered for each local system of provision as a whole, based on whole populations of 200-300,000.

21. Each provider should adopt a planned approach, including sequencing, to the whole system of mental health service organisation and service development in their area:
    - all statutory and independent providers must be fully engaged and involved

– representative service users and carers must be involved in service planning, development, delivery and monitoring

– service vision, plans and strategy should be needs driven, based on local assessment

– the needs of specific service users must be considered:
  - younger people and older adults
  - adults with mild learning disability
  - current long stay residents in mental hospital settings
  - the mental health needs of people in general hospital settings
  - people requiring specialist services (Chapter 6)

– the interface with Forensic, Alcohol and Substance Misuse Services, Services for Younger People and Older People must be included within service plans for Adult Mental Health.

22. Services must be underpinned by good managerial cohesion, information management, team working and communication.

23. Provider units must have a comprehensive workforce strategy embracing recruitment, retention, training, support and supervision tailored to the specific needs of staff and work requirements. This must address specific training needs of specialist services and primary care mental health training. Training should be multidisciplinary and include teamworking and leadership skills, as well as therapeutic skills.

MENTAL HEALTH NEEDS

4.14 From a user perspective the various elements of services required to meet individual mental health needs must be available and accessible. In the planning and delivery of services a user perspective on the pathways into, through and out of services is essential. Such a perspective emphasises the importance of the connectedness of services, patient and carer information appropriate to their situation, and the maintenance of hope for recovery and restitution through the provision of appropriate services and supports.

4.15 A modern mental health service consists of a complex set of activities and functions designed to meet the needs of individual service users. From a person-centered and needs perspective, the complement of mental health services can be considered in three domains:

- living in the community;
- times of crisis, including acute episodes of mental disorder and social difficulty; and
- promoting recovery of health, personal functioning and fulfilment.

Each of these is considered in detail below, followed by a review of the needs of people with specific service requirements, therapeutic interventions and physical health needs.

Living in the Community

4.16 For people whose mental health needs cannot be met within primary care, ready access to mental health services is essential. The Community Mental Health Team (CMHT) with its close links to primary care forms the cornerstone of person-centred secondary services.

4.17 **Community Mental Health Teams**. Throughout most of Great Britain generic CMHTs have become the basic building block of community mental health services.[2] CMHTs are central to supporting service users and their families within community settings and for supporting the mental health work of Primary Care Teams.[3, 4, 5] Within this Strategic Framework, CMHTs are considered central to the care of the majority of people with mental health problems in the community requiring secondary services, including tier 2 services for people requiring specialist services (Chapter 6).

4.18 **Person-centred services**. A central advantage of generic CMHTs is their ability to provide a wide range of services and continuity and flexibility of care. Service users may, at times, require intensive contact, for example during a relapse, and at other times require relatively low levels of support. People with complex and enduring mental health needs arising from their mental disorder should be provided with a yearly multi-disciplinary review including review of care plans, physical health and risk assessment.[6]

4.19 In many places CMHTs are undergoing a process of change, but their core functions remain. The wide spectrum of service user needs has led to a differentiation of functions within or between established CMHTs with a focus on either primary care liaison or services promoting recovery. These services are considered in detail in subsequent sections.

4.20 The effectiveness of CMHTs is dependent on a number of factors:

- Resources. Teams must be adequately staffed by a range of health and social care professionals, including social work, nursing, occupational therapy, support workers, clinical psychology and medicine. There should also be ready access to specialist psychological therapy services. One advantage of larger catchment-based services (50,000) is a corresponding enlargement of CMHTs to provide a greater range of skills, competencies and increasing patient choice. Based on the service mapping data in England in 2004, the median provision of community staffing was 78 staff/100,000 adult population.[7] For Northern Ireland this is equivalent to 50 staff/100,000 whole population.
- Skills. Staff must be appropriately skilled and competent to respond to the range of health and social needs of service users embracing a wide spectrum of treatments, support, care, health promotion and relapse prevention. There should be a facility for continuing professional development and mechanisms for supporting staff.
- Information. CMHTs must have access to a detailed knowledge of the number and needs of individuals with severe mental health illness in their area.
- Effective Team Working. Staff require effective team working skills. There must also be effective team leadership and team management. The integrity of the team – issues such as professional accountability, agreed policies on confidentiality and information sharing - need to be agreed.
- Access. The boundaries for teams need to be agreed with local stakeholders. Access arrangements need to be clear and transparent to service users and carers. Primary care's relationship with its local CMHT is fundamental to effective working. The team's relationship with the local A&E department, the Liaison Mental Health Service (LMHS) and the Home Treatment (HT) service should be clear (see 4.91).

4.21 Although a key building block, CMHTs cannot work in isolation. They must develop appropriate relationships with other mental health services. Access to a range of day-time facilities and accommodation is essential. Effective working relationships with primary care, day care, day hospital and inpatient services are fundamental. Within a given service sector Primary Care Teams must have ready access to a CMHT (See Chapter 3). This may be achieved by a CMHT being based in a primary care setting or a mental health professional working in primary care supported by or part of a CMHT (see Chapter 3). Where appropriate, effective access arrangements should be assured for the student health and counselling services within further and higher education. Primary care provision for people with more complex mental health needs must be determined locally and requires the development of shared care protocols.[8]

4.22 Access to a range of non-healthcare services, including employment agencies (see 5.8) and housing agencies (see 5.16), voluntary and user-led facilities are essential. Co-locating services to the workbase of CMHT can provide a One Stop Shop for services and improve access and efficiency.

Recommendations

24. Community Mental Health Teams should be established so as to provide comprehensive coverage of each provider unit's population as an essential element of future mental health service provision. They must have or be provided with detailed information on the numbers and needs of individuals in their area, particularly those with more complex and enduring needs.

25. CMHTs must be adequately staffed with a range of health and social care professionals. A minimum provision of 50 care staff/100,000 whole population, including community rehabilitation is recommended.

26. Where CMHTs are providing input to primary care, then the seamlessness of provision must be addressed, including the identification of a named individual on the CMHT for primary care staff. In addition to service support, such input has an important educational role (see Chapter 3). The relationship with primary care, A&E and HT services should be clearly defined and agreed by both provider and referring services.

27. CMHTs must have access to and good interface arrangements with a range of community facilities and services, including day hospitals, day activities, special accommodation including respite facilities, vocational and leisure services, independent and user-led facilities. Where other community teams, for example, HT teams, are separate from CMHTs, then good interface arrangements are essential.

28. People with more complex and enduring mental health needs should be provided with a yearly multidisciplinary review, including review of care plans, physical health and risk assessment. The participation of service users and, where appropriate, their key carer in the preparation and review of care plans is essential for person-centred care.

In Times of Crisis

4.23 People with more complex and enduring mental disorder often experience acute difficulty or need which may arise through relapse of their mental disorder or through problems in coping with the demands of their social and personal situation. At present the most common service response to people in such situations is admission to hospital.

4.24 Present evidence suggests that conventional community services, including CMHTs working within normal working day arrangements are unable to respond adequately to the needs of people with severe mental health problems at times of urgent need. Research also suggests that up to one third of inpatients could have been provided with therapeutic interventions and care in more appropriate settings. [9, 10, 11, 12]

4.25 **Home Treatment/Crisis Resolution.** Home Treatment/Crisis Resolution has been introduced in a number of western countries as a community alternative to inpatient hospital care. The purpose of modern HT services is to provide flexible assessment and home-based treatment, care and support, as an alternative to inpatient care on a 24 hours a day 7 days a week basis. The introduction of HT is greatly appreciated by service users and families and can make a significant impact on the requirements for inpatient admission.[11,13,14] HT teams typically have a time-limited role (weeks) but nevertheless assume responsibility for the period of acute need. Referals are accepted from General Practitioners, A&E departments, social services departments. Arrangements may also be made for HT teams to respond to the needs of mentally disordered people in police stations.

4.26 A second function of HT is to provide a gatekeeper function for hospital admission which can make an impact on the requirement for admission.[11,13,14,15] Teams can also facilitate the early discharge to home of patients admitted to hospital.[16] Together these impact on inpatient service requirements. HT services may be a stand alone team or a sub-function within a CMHT (see Configuration of Services 4.118).

4.27 More research is required on the various elements that may optimise the functioning of HT and on their relationship with CMHTs. Nevertheless key elements found to be central to effectiveness include:

- Policy. Services must be targeted – specifically the needs of those who would otherwise require admission to hospital. Typically people with acute psychosis, people with relapsing chronic mental disorder, severe depression or acute reaction to severe stress.

- Philosophy. HT is premised on the view that the management of a person's problems can be achieved within a community setting.
- Assessment – a comprehensive initial assessment is fundamental with access to multiple sources of information. This should embrace clinical, social and risk assessment.
- Planning. Flexible plans prepared in collaboration with the service user and, where appropriate, their key carer is essential. All participants in the situation must understand the plan.
- Management. Action plans must address practical problems, for example accommodation, financial issues. Treatment must be at the point of need. Follow-up frequency must be appropriate to the needs of the situation. HT team members must aim to build a trusting relationship with the user and carers. The HT team remains involved until the crisis is settled. For people with enduring mental health needs involvement of the key worker from the CMHT facilitates continuity of care.
- Gatekeeping. HT teams must interface efficiently with primary care and A&E services on the one hand and be given a clear gatekeeping function for hospital admission on the other. HT teams must be closely integrated with all elements of crisis services – acute inpatient, acute day hospital and crisis arising in the work of CMHTs.
- Skills. Staff require appropriate skills to deal with a range of healthcare and social situations.
- Resources. HT teams must be appropriately resourced and supported including the availability of crises houses.

4.28 The Review strongly recommends early consideration of HT services. Adequately resourced HT teams with clear gatekeeping functions can significantly reduce the pressures on inpatient services and CMHTs while providing users with increased choice of provision at times of crisis. Over time, as HT becomes a dominant characteristic of recovery services, HT teams should become part of Recovery CMHTs (see 4.121).
Good Practice Examples (Annex 5.4.1)

4.29 If a person cannot be maintained in their own home an effective alternative to hospital is community step-up residential care.[17,18]
Good Practice Example (Annex 5.4.2)

4.30 **Day Hospital Services**. Acute day hospitals should be considered as a cost-effective option for the provision of acute care both as an alternative to acute admission to hospital and to facilitate early discharge from inpatient care.[19] A recent systematic review identifying 9 randomised controlled trials found that day hospital treatment was a feasible alternative to inpatient admission in between 23% and 38% of instances. There is also evidence of greater satisfaction among patients and no evidence of increased burden on carers. The cost-effectiveness of this model of provision over home treatment is an important consideration.[20] Within a modern community focused service Day Hospitals are an important element in Crisis Services, provide a valuable step-down function and a base for Community Teams.

4.31 Day hospitals can also provide an important base for Recovery Services (see 4.38) and for specialist services, for example, Eating Disorder and Personality Disorder services (Chapter 6).
Good Practice Example (Annex 5.4.3)

4.32 **Inpatient Provision**. Acute inpatient care is an integral part of mental health services. In the context of well-developed community services, inpatient admission should only be required for people with most severe episodes of mental disorder, typically psychosis and severe depression. Improving the quality of inpatient care and its integration with the other key elements of the whole system of service provision form an essential part of this Framework.

4.33 Several reports, including reports from service users and from the Northern Ireland Association for Mental Health on inpatient services, have highlighted significant shortcomings and dissatisfaction with current provision.[11,21-24] From a service user perspective, if a period of inpatient care is necessary, this must be of high quality and provide an appropriate range of therapeutic interventions and services including, where necessary, intensive care. (see 4.65).

4.34 A small number of people with severe and enduring mental health problems will require the safety and security of hospital provision for lengthy periods of time, for example people recovering from severe brain injury, people suffering from psychosis with ongoing high risks to themselves or others (see 4.63). While there is a need for a better evidence base on inpatient services, several reviews and surveys provide strategic pointers for addressing present shortcomings.[11, 22, 23, 25]

4.35 **System of Care.** A single system of co-ordinated acute and crisis care is fundamental for service effectiveness. In particular, there must be joint working between inpatient and HT services. Inpatient services work best when they are close to the service user's local community, maximising their connections and integration with community mental health services, including CMHTs and supports.[15, 26] Such connectedness can be facilitated by the formation of Acute Care Fora involving representative users and carers along with service providers, with clear accountable links to Trust management.[21] While the Royal College of Psychiatrists recommends inpatient units are best located on district general hospital sites, [23] Boards and Trusts should explore the full range of choices for providing care.

4.36 **Milieu and Environment.** Service user-centred provision is a fundamental principle which should underpin inpatient services. Service users require individual care plans specific for their needs. A range of therapeutic resources must be available appropriate for need. The hospital environment must be designed to deliver a relaxed, secure and non-stigmatising atmosphere. Provision must be appropriate for gender and cultural needs.

4.37 **Leadership and Staffing.** Clinical and professional leadership is essential for ensuring co-ordination across the Acute Care system. Staff must also be provided with support and supervision. Staff levels and skill mix must be appropriate for service user needs and staff must be provided with opportunities for education, training and professional development.

Recommendations

Home Treatment Services

29. HT services must be available and accessible to each provider's catchment area, on a 24 hour basis subject to demand, accessible to general practitioners, A&E departments, CMHTs, social services and police.

30. There should be a single system of co-ordinated acute care, including step-up community residential care and inpatient provision. HT services must become the gatekeeper for hospital admissions.

31. HT teams must be appropriately resourced and skilled to deal with the range of healthcare and social situations for people in mental health crisis, their carers and families, including risk management.

Day Hospitals

32. Within each Trust consideration should be given to providing day hospital provision as an alternative to acute admission and complementing HT teams.

Inpatient Services

33. Acute inpatient services should be based in well-designed facilities and close to the community they serve such as general hospital sites.

34. The quality of inpatient services should be the subject of both regional and local review. Services must be of high quality and provide an appropriate range of assessments, therapeutic interventions and services including intensive nursing services. They must deliver a therapeutic and safe atmosphere and be sensitive to gender and cultural needs.

35. Each provider must designate a lead clinician or manager to take overall responsibility for inpatient services.

Promoting Recovery

4.38 Central to recovery from a mental disorder is regaining control of one's life. Individuals who have experienced recovery highlight the importance of hope, self esteem, empowerment and social connectedness.

> "A person with mental illness can recover even though the illness is not "cured" …Recovery is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in ones life and as one grows beyond the catastrophic effects of mental illness. (Dr W A Anthony, 1993)"[27]

4.39 For people with more complex and enduring mental health needs, a diverse range of services is required to promote recovery, tailored to individual needs and circumstances. They have, by definition, greatest need and should be afforded the highest priority. Services are also required to give carers the information, skills and support necessary to assist them in their caring role and to minimise the stress associated with that role.[28] In this section, detailed consideration is given to the needs of people with more complex and enduring needs and the services necessary to meet these, including Rehabilitation Services and Assertive Outreach Services. Some people have special needs including needs arising from challenging behaviour, co-morbid substance misuse, growing older. They may also have secondary problems related to income (see 5.32) and accommodation (see 5.16). These issues are dealt with in subsequent sections.

4.40 Research, including local research, has shown deficiencies in services particularly in the areas of psychological and social provision[29,30] including provision for educational needs, work-related activity, domestic functioning and socialisation and also emotional needs (see Chapter 5).[29]

4.41 The needs of this group of people often cannot be met fully by current generic CMHTs and require specialist community services, for example, by sub-specialisation of or within CMHTs.[31] People with complex needs require service responses which guarantee continuity, flexibility and accessibility.[32] This can be facilitated by Care Plans and consideration of their individual Care Pathways, based on a multi-disciplinary approach and the involvement of users and, where appropriate, carers in the planning arrangements.[33]

4.42 When people with complex and enduring needs no longer require the intensive provision of acute services they may still, for a time, require a range of supportive services within an appropriate residential environment. Such “step-down” facilities need not be within a hospital setting and may often be more appropriately provided in the community and nearer to home. Nevertheless their functional integration with acute services is essential.[34,35] The continuum of provision includes services led by service users.

4.43 Given the aim of full community integration, every effort should be made to destigmatise and normalise aids to recovery, making maximum appropriate use of mainstream facilities and resources.

4.44 Essential professional skills to promote social integration for service users include:[31]

- prescription and supervision of complex medication regimens;
- evidence-based psychosocial interventions;
- training/support for independent living skills;
- training for vocational skills;
- evidence-based psychological treatments, including family work;

- social skills training; and
- financial management.

4.45 In the context of community based recovery and longer term support the role of carers is often pivotal. In addition to their own health needs they require and can greatly benefit from formal education, training and support for their caring role (see 5.62).
Good Practice Examples (Annex 5.4.4)

4.46 **Assertive Outreach.** A small number of people with complex mental health needs have difficulty maintaining involvement with the services they require. As a result, they are at high risk of relapse which would require readmission to hospital. Present evidence suggests that Assertive Community Treatment (ACT) is a successful alternative to inpatient hospital treatment, enabling service users with the highest levels of disability and greatest vulnerability to be maintained more successfully in community settings.[34-41] Effectiveness depends on small caseload and on staff having the necessary skills.[42, 43]

4.47 ACT sits best within the spectrum of services promoting recovery, enabling the most vulnerable and severely mentally ill to move more easily from inpatient settings to community settings and reducing the need for lengthy inpatient stays.[44,45] Present evidence[46,47,48] demonstrates that Assertive Outreach* can:

- improve engagement;
- reduce hospital admissions;
- reduce length of stay when hospitalisation is required;
- increase stability in the lives of service users and their carers/family;
- improve social functioning; and
- be cost-effective.

4.48 The goal of Assertive Outreach is to increase stability within the lives of service users, to facilitate personal growth and provide opportunities for personal fulfilment. Fundamental to the effectiveness is the establishment of meaningful engagement with service users. The aim is to provide a service that is sensitive and responsive to users' needs and supportive to service users and their families over sustained periods of time. This must include effective risk assessment and risk management. ACT services must also ensure effective

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*The term Assertive Outreach is used in this context to refer to the availability of an Assertive Community Team.

liaison with community forensic services. While treatment support and care for this group of people will usually be required on a long term basis, this need not necessarily be provided by ACT.

4.49 Assertive Outreach cannot work effectively in isolation. The generic needs of this group of users are similar to all people with mental illness. These include the need for adequate income, accommodation, meaningful day time activity, support with daily living, in addition to both primary care and specialist mental health interventions.[49] This, in turn, depends on a readily available range of services, including suitable supported accommodation, a range of daytime activities including employment opportunities, clear arrangements for accessing safe 24 hour care.

4.50 While more research is required on the specific elements of Assertive Outreach which contribute to service effectiveness, present evidence suggests two key features. First, staff must be appropriately skilled [39, 49, 50] in:

(i) assessment – embracing mental state, general functioning, needs and risks;

(ii) planning – including care planning and management;

(iii) interventions with service user and families including medicine management and concordance, problem solving and goal setting, issues surrounding dual diagnosis, information and education, family interventions;

(iv) social support with housing, education, work and welfare benefits; and

(v) multi-disciplinary team working.

Second, ACT must be adequately resourced. The Royal College of Psychiatrists recommends an optimal team size of between 8-10 FTEs with social work, nursing, occupational therapy, clinical psychology and medicine as essential disciplines.[31] An optimal caseload for individual care co-ordinators is about 12.[39, 5] The relationships among services promoting recovery, CMHTs and ACT teams need to be carefully planned, appropriate for local needs. *Good Practice Example (Annex 5.4.5).*

Recommendations

36. The service requirements of people with complex and enduring mental health needs should be given the highest priority and clearly defined for each Trust's catchment area.

37. Identifiable services promoting recovery should be established within each Trust for people with complex needs and providing comprehensive coverage of the Trust area. Care plans embracing risk assessment should be provided based on a multidisciplinary and when required a multi-programme approach. Risk assessment should include accommodation needs. Users and, where appropriate, carers must be involved in care planning.

38. A comprehensive range of community services must be available to facilitate recovery for people with complex needs. The introduction of step-down facilities should be considered to facilitate discharge from acute inpatient care.

39. Every effort must be made to destigmatise and normalise, making maximum appropriate use of mainstream facilities and resources.

40. ACT should be provided for service users with highest levels of disability and greatest vulnerability, particularly those who have difficulty maintaining links with existing services.

41. ACT teams must be adequately resourced – an optimal individual caseload for delivering care is 10-12.

People with Specific Service Needs

(i) Younger People

4.51 The Review envisages a substantial development in young people's services. Nevertheless, there is a need for flexibility and, where appropriate, joint working appropriate for the needs of individuals. It is essential that there are seamless transitional arrangements for people whose mental health problems arise in childhood and extend into adult life. These should include specific plans for:

- younger people with psychotic illness that may require lifelong care;
- adults with developmental disorders such as autistic spectrum disorders, learning disability and attention deficit hyperactivity disorder; and
- adults with mental health problems arising from adverse childhood experiences including people who are survivors of abusive experiences.

4.52 While a comprehensive adolescent service must include appropriate inpatient facilities, the reality at the present time is a deficiency of such places. It is wholly unsatisfactory that older adolescents are admitted to adult inpatient units. Nevertheless, until additional adolescent inpatient facilities are established, it is essential that there are agreed flexible arrangements at local level to allow, where necessary, young people to be admitted to adult inpatient facilities.

4.53 Further consideration on the interface between Child and Adult Services is given in the Review of Child and Adolescent Mental Health Services which is the subject of a separate report.

4.54 **People with a first episode of psychosis.** There have been growing concerns regarding the shortcomings of service provision for younger people, both adolescents and young adults, with severe mental disorder. These arise from the evidence that delays in first treatment may lead to poor outcomes both the short term and long term.[51, 52] Surveys of services by Rethink have highlighted delays on average of twelve months between onset of psychotic symptoms and initiation of treatment. They also report services to be insensitive to the needs of younger people including their training and employment needs.

4.55 Emerging evidence suggests that early intervention, embracing assessment, medical and psychological treatment and appropriate assistance with training and educational needs, can improve recovery and social functioning.[53-56] General Practitioners are key pathway players. Based on current evidence the NSF Implementation Guidelines[5] suggest the following principles for service provision:

- separate, age-appropriate facilities for younger people;
- emphasis on service users' needs including support, education and employment;
- family-orientated services;
- age, gender and culture sensitivity;
- treatment provided in the least restrictive and stigmatising setting; and
- emphasis on managing symptoms rather than diagnosis.

4.56 The aims of early intervention are:

- to encourage liaison between primary/secondary care in the early detection and management of the first psychotic episode to reduce duration of untreated psychosis;
- early effective interventions to accelerate remission and prevent relapse, including pharmacotherapy and adjunctive psychosocial interventions;
- normalising experiences and reducing adverse consequences of trauma, depression and suicide; and
- maximising social, educational and work functioning.[57]
  Good Practice Examples (Annex 5.4.6)

Recommendation

42. Separate age-appropriate services for younger people with a first episode of psychosis should be established. Services should be gender and culture sensitive.

(ii) Adults with Mild Learning Disability

4.57 The majority of people who have a mild learning disability live in society without formal additional support and may be well-integrated into their communities. While not necessarily disabled in their daily functioning, by their intellectual impairment they are at increased risk of mental disorder[58]. Mental disorder in addition to pre-existing intellectual impairment may be disabling. Adults with mild learning disability and their carers wish to access health services as other adults including, where appropriate, Adult Mental Health Services.

4.58 The Royal College of Psychiatrists[59] endorsed informal examples of good practice in Northern Ireland where adult mental health services and learning disability services co-operate to provide treatment and care for people with various degrees of learning disability. Community based models of treatment in both programmes are broadly similar although differ in resources and skills.

4.59 Services should be based on individual context and a comprehensive assessment of need. Continuity of care is of great importance for people with a learning disability.

4.60 Fuller consideration of the mental health needs of people with learning disabilities is given in the Equal Lives Review.

Recommendations

43. Adults with mild learning disability should be facilitated in accessing adult mental health services as a first preference. The preferences of people already within either adult mental health services or learning disability services should be respected.

44. Adult mental health services should be resourced to include people with mild learning disabilities. Additional time and expertise are required for assessment and for consultation between professionals within and across programmes of care. Co-operative working, sharing of facilities and expertise between adult mental health services and learning disability services must be established in each Trust area.

(iii) People Becoming Older with Enduring or Relapsing Mental Illness

4.61 With increased life expectations generally more people with major mental disorders such as schizophrenia, bipolar affective disorder , organic brain disease, severe depression, are living into later life. Given the separate development of health and social service services for older people it is essential that there are locally agreed arrangements for service provision for people within adult mental health services who reach 65 years of age. As noted by the Royal College of Psychiatrists, [60] graduation from one age group to the next offers an important opportunity to review treatment and care needs including any comorbid physical illness. Such a review by the lead service providers should include social needs including accommodation, support, and the needs of carers.

4.62 Further consideration on the interface between Adult Services and Services for Older People is given in the Review of Mental Health Issues of Older People which is the subject of a separate report.

Recommendations

45. Local arrangements for meeting the needs of people who enter old age with enduring or relapsing mental disorder must be agreed. Where individuals graduate from adult mental health services to services for older adults, therapeutic and care needs should be the subject of review .

46. Local population needs of people entering older age and their carers should be assessed.

(iv) People with Challenging Behaviour

4.63 Within adult mental health, the term 'challenging behaviour' refers to people who are suffering from a serious mental illness, for example schizophrenia or sequelae of head injury and who, in addition to severe and often persistent symptomatology, show a range of behavioural problems, such as aggression, violence, repeated self-harm, extreme self-neglect, fire-setting or inappropriate sexual behaviour.[61-63]

4.64 The majority is young males, most of whom have schizophrenia, whose disorder is poorly controlled and have co-morbid drug and/or alcohol misuse.[61] Second, is an older group, often with treatment resistant bipolar disorder, which is likely to account for a further 20%. Third, is a group with significant cognitive impairment due to acquired brain damage, alcohol misuse, pre-senile dementia or psychosis associated with severe cognitive decline. Estimating the numbers in each category is difficult. Wing [65] suggests that, for specialist residential care for this group, between 10 and 30 places per 100,000 might be needed.

4.65 **Therapeutic Options.** Specialist Supported Living. Residential provision for this group of service users attempts to combine the best features of hospital care (high staffing levels, intensive professional input, individualised programmes of care) with a setting that is both homely and domestic in scale and operation. A range of residential provision is essential including the use of the "ward in a house" and the "hospital hostel". [66] The emphasis must be on improving and maintaining functioning rather than simply symptomatic improvement.

4.66 Intensive community support. Present evidence favours the use of Assertive Outreach for people with psychotic disorders who relapse frequently, requiring hospital admission and with low engagement with services and concordance with treatment. [67] People targeted for Assertive Outreach services have complex needs, including challenging behaviour.

4.67 Hospital treatment and care. The following definitions were developed by a multidisciplinary practice development network as part of their work in developing national minimum standards for Psychiatric Intensive Care Units (PICU) and low secure units, and published by the Department of Health.[68]

4.68 'Psychiatric intensive care (PICU) is for patients compulsorily detained usually in secure conditions who are in an acutely disturbed phase of a serious mental disorder. PICUs must be part of acute inpatient services. They should provide a comprehensive range of activities and therapies, underpinned by a core philosophy of risk assessment, risk management and intensive engagement.'

4.69 'Low secure units deliver intensive, comprehensive, multidisciplinary treatment and care by qualified staff for patients who demonstrate disturbed behaviour in the context of a serious mental disorder who require the provision of security…. Patients will be detained under the Mental Health Act …. needing rehabilitation for a period of up to 2 years'.

4.70 Secure locally-based NHS facilities are also part of a seamless forensic service. The Reed Report[69] into services for mentally disordered offenders and others requiring similar services, proposed that, in addition to medium secure facilities, access to local intensive care facilities should be available more widely and that 'secure provision should include provision… for those who require long-term treatment and/or care'.

4.71 The Cavan/Monaghan project[70] recommends that patients who have enduring disturbed and challenging behaviour in the context of mental illness require care in a specialist unit, possibly provided on a regional basis in view of the very small numbers of people requiring such facilities. A policy statement from Rethink[71] stated that sufficient secure facilities should be available for those who need them, that they should be locally based and used for the shortest possible time.

4.72 Further consideration on the interface with Forensic Services is given in the Review of Forensic Services which is the subject of a separate report.

Recommendations

47. Service providers must plan for the needs of people with challenging behaviour:

- community mental health services with the capacity to provide intensive support
- specialist accommodation with appropriately skilled staff (see recommendations).
- local intensive care
- low secure inpatient services with a recovery ethos and with links to Community Recovery and Assertive Outreach services.

48. Low secure units can function as 'step-down' services from the Regional Secure Unit.

49. Longer term high quality hospital provision is likely to prove necessary for a small group of people whose behavioural problems are often chronic and severe.

(v) People with Mental Health Needs Subject to the Criminal Justice System

4.73 People with mental disorder may, like other members of society, become subject to the criminal justice system. Thus, people with mental disorder may be found in police stations, on bail, attending court, on probation, in prison or recently released from prison. Not all of the people require designated forensic services to meet their mental health needs. Adult mental health services must co-ordinate effectively with forensic services to address the needs of each individual, including those who are transferred from forensic services. There is a need for co-ordination in the development of services and for a training strategy to support adult mental health services. This is likely to involve the work of CMHTs including, where appropriate, inreach services to prisons (see 4.17). Further consideration on the interface with Forensic Services will be given in the report on the Review of Forensic Services.

Recommendation

50. Service providers must ensure co-ordinated development of adult mental health and forensic services.

(vi) People with Co-existing Substance Misuse and Mental Health Problems (Dual Diagnosis)

4.74 While the term "dual diagnosis" is unsatisfactory as personality disorders and serious medical problems are also frequently present in those with a history of substance misuse and mental health problems, it is retained here as other alternatives are less succinct. Providing high quality care to those with a dual diagnosis of concurrent mental health problems and substance misuse problems- alcohol and/or drugs – has been identified as a major challenge for mental health services.

4.75 Concerns have been raised that people with a dual diagnosis have fallen between the mental health and addictions services.[72] The Safer Services report[73] recommended that people with concurrent severe mental health problems and substance misuse should be managed within mainstream mental health services. The commonest co-morbid disorders are anxiety states, affective disorders and personality disorders.[74]

4.76 Drug use in inpatient units is an increasing cause of concern in the UK. Some service users with dual diagnosis may continue to use alcohol or drugs in acute inpatient units.[75] There is also evidence that the routine assessment of alcohol or drug use at the time of admission to acute units markedly underestimates substance misuse problems.[76]

4.77 **Substance misuse, suicide and homicide**. Substance misuse is an important risk factor of suicide and homicide. In Northern Ireland, the estimated risk of suicide in the presence of current alcohol misuse or dependence was found to be 8 times greater than in the absence of current alcohol misuse or dependence.[77] The National Suicide Prevention Strategy for England (2002) identified the need for mental health services to implement local strategies for dual diagnosis covering training on the management of substance misuse, and joint working with substance misuse services.[78]

4.78 **Substance misuse and co-existing physical disorders**. The health problems associated with alcohol and drug misuse are widespread. People with a history of injecting drug misuse are particularly at risk from overdose, infections and blood borne viruses such as hepatitis C and to a lesser extent hepatitis B and HIV. The highest risks of premature death from natural and unnatural death for common mental disorders are for substance misuse and eating disorders. Opioid dependence and abuse had a mortality risk for suicide of 10 times that expected, for violent deaths 13 times that expected and for natural deaths 4 times that expected.[79]

4.79 **Management and Services Models**. Guidance on good practice in relation to people with a mental disorder and also alcohol or substance misuse reflect the complex interactions between substance misuse and mental health problems.[80-85] Three main models of service delivery have been proposed for people with dual diagnosis; serial, parallel and integrated.

4.80 The serial treatment model proposes mental health and substance misuse disorders are treated consecutively For example, patients presenting to mental health services with a substance-induced mood disorder which subsequently quickly resolves following a brief period of abstinence would then be appropriately referred on to addictions services. In the parallel treatment model concurrent input is proposed by substance misuse services and mental health services. However this may create tensions in treatment delivery between the two services. In the integrated treatment model treatments for both psychiatric and substance misuse are provided within one clinical team. Specialist integrated services have been established in both the USA and UK for people with dual diagnosis.

4.81 While there is a lack of sound evidence on the relative effectiveness of these models[86] current UK guidance strongly supports an integrated treatment model delivered within mainstream services by mental health staff who are appropriately trained in substance misuse. The National Treatment Agency for substance misuse have been developing modules of care for the treatment of drug misusers, including care pathways, which will incorporate issues pertinent to dual diagnosis workers.[87]

4.82 Further consideration on Dual Diagnosis services is given in the Review of Alcohol and Substance Misuse Services which is the subject of a separate report.

Recommendations

51. Trusts should make provision for people with mental health problems and co-existing alcohol or drug misuse. Local prevalence and needs of people with dual diagnosis should be assessed.

52. People with co-existing substance misuse and mental health problems should be treated using an integrated treatment model within a single service.
    - The needs of those with complex, enduring and relapsing mental disorders can best be met by adult mental health services.
    - The needs of those with less severe mental health problems, whose main difficulties are directly related to substance misuse, can best be met by substance misuse services.
    - Agreed arrangements need to be established between any specialist services for people with personality disorder and substance misuse services.
    - There should be systems of liaison between substance misuse and other mental health services to ensure that people with a dual diagnosis have access to the full range of the most appropriate treatment services.

- Physical health problems associated with substance misuse need to be identified and addressed.

53. The needs of people with co-existing substance misuse and mental health problems in contact with the criminal justice system should be identified and addressed.

(vii) People in General Hospital Settings

4.83 Mental health services are required to address the needs of people with mental health problems presenting in general hospital settings. There is increasing recognition of the high prevalence of mental health problems in general hospital settings, both inpatient and outpatient. The following are the most common.

4.84 **Deliberate Self-Harm**. The frequency of deliberate self-harm (DSH) has risen steadily since the 1960s and currently there are 140,000 such presentations per year at general hospitals in England and Wales with this behaviour.[88] The individual intent in DSH varies. Underlying the act of self-harm there are a variety of situational, addictive and mental health disorders that require accurate assessments. Between 5-20% of people who present with an act of deliberate self-harm require urgent psychiatric admission for their own safety.[89] In the year following an attempt of self-harm about 1% commit suicide. There is a significantly higher rate of suicide after self-harm in those who are not adequately assessed.[90]

4.85 **Alcohol and Drug Misuse**. Alcohol misuse contributes to 20-25% of all general hospital admissions.[91, 92] Alcohol misuse is a risk factor for many serious health problems including cancers, heart disease, stroke, accidents and suicide. Screening for alcohol misuse in a general hospital setting is simple and effective. There is also clear evidence of the efficacy of brief interventions to reduce alcohol misuse in those identified and appropriately counselled.[93]

4.86 **Organic Brain Syndromes**. Dementia is common in general hospital populations reflecting the age profile of patients today. Prevalence rates as high as 35% have been reported, increasing with age. Delirium is also common with prevalence rates in general hospital patients of up to 60%. This is particularly common after cardiac and hip fracture surgery and again with increasing age. Both dementia and delirium are important indicators of physical illness and are associated with increased mortality and increased length of stay in hospital.

4.87 **Medically Unexplained Symptoms.** Some people present with physical symptoms for which there is no obvious underlying physical cause, or where symptoms are disproportionate to any underlying medical disorder. In many but not all, the presentation is associated with underlying mental health problems. While such conditions are known by a variety of different terms, "medically unexplained symptoms" is to be preferred, as this does not imply any specific cause. Medically unexplained symptoms account for 40-50% of service users in hospital outpatient clinics. The more physical symptoms that people report, the greater the likelihood of associated mental illness regardless of the nature of their symptoms. Appropriate psychological intervention can reduce such functional somatic symptoms, generally best tried initially by the treating physician with mental health specialists involved where problems are more intractable.[93]

4.88 **Behaviours and Emotional Reactions Impacting on/or associated with Medical Care.** Lifestyle issues account for a significant proportion of physical illness. Smoking for example, despite education regarding its negative consequences, risk taking behaviours, which negatively affect physical morbidity or mortality, may be helped by specific psychological interventions. The emotional needs of people with physical health problems may require specific psychological interventions in addition to general support.

4.89 **People with Physical and Mental Ill-Health.** Given that mental health problems are common, many people admitted to general hospitals may have unconnected mental disorders, which may require advice or adjustment of treatment because of the associated physical difficulties.

4.90 It is important that medical specialists should have access to Liaison Mental Health services to allow input where necessary[91] particularly to the above groups of people.

4.91 A multidisciplinary Liaison Mental Health Service (LMHS) provides the best means of ensuring effective methods of dealing with the mental health needs of service users in a general hospital setting.

4.92 Liaison Teams are also suitably placed to provide education and to improve the knowledge and skills required to treat people with mental health problems and learning difficulties in general hospital settings, regardless of whether or not they need to be referred to specialist services.

4.93 **Identification and Assessment of Needs.** It is generally acknowledged that the identification of mental health problems in general hospital settings is poor. Identification is based on clinical assessment, history taking and mental state assessments, supplemented by other sources of information. Whilst it may sometimes be difficult, staff should endeavour to identify admitted patients who have a mental health problem, learning disability or dementia and any special needs they may have arising from this. Where appropriate and with the person's consent additional information should be sought from key informants. Appropriate information and education should be provided to general hospital staff to enable them to undertake psychosocial assessments. Ward staff should liaise with professionals in the community.

4.94 **Stigma.** People with mental health problems, learning disability or dementia have the same fundamental rights as any other person, including rights to the same standards of health and social care. General hospital staff should be trained in mental health awareness to prevent medical patients with mental health problems feeling stigmatised or prejudiced. They should also have access to an advocate, should they wish to avail of this.

4.95 **Care Environment.** General hospital staff should consider the immediate environment of patients in terms of physical needs, safety and where appropriate potential risk of deliberate self-harm. Staff undertaking such duties should have adequate training in the care of patients with mental health needs. It may be advisable that specific staff or units are allocated such patients because of familiarity and experience in dealing with the above difficulties.

4.96 **Referral to Liaison Services**. On occasion referral to a mental health specialist is appropriate for assessment, advice and management of a service users' mental health problem. Referral should be to a LMHS, a multi-disciplinary team that may typically consist of a liaison nurse, social worker, clinical psychologist, psychiatric trainee and consultant psychiatrist. The LMHS should provide prompt and, ideally, same day assessment to assess risk, identify mental illness, and advise on physical and appropriate psychological treatments and follow-up. The LMHS team can also give specialist advice regarding the use of the Mental Health (Northern Ireland) Order 1986 and offer training and education to hospital staff for identification and management of mental health problems in the general hospital setting.

4.97 Because of potential dangers in certain presentations, it is important that the LMHS team can respond quickly (usually within one hour) if requested. There is a need for clear referral protocols from the general hospital ward. It is also important that the LMHS team have effective patterns of communications with General Practitioners and other mental health professions, allowing clear aftercare plans to be made prior to the service user leaving the general hospital.

4.98 In view of the sensitivity of many of the issues surrounding mental health in the general hospital setting, it is important that consultation arrangements ensure comfort, privacy and security for service users and for the mental health professionals involved. In view of the unpredictability of crises, it is important that appropriate services are available 24 hours per day, 7 days per week.

4.99 **Accident and Emergency (A&E) Services**. The range of presentations noted above can present to A&E departments and often in a more acute state than on a general hospital ward.[94] It is important therefore that departments have appropriate access to Mental Health services 24 hours per day, 7 days per week. The speed of response is imperative because of the potential dangers of severe untreated mental health emergencies but also to alleviate distress to waiting service users and their carers. Agreement will be required between LMHS teams, HT teams and CMHTs regarding nature and configuration of services (see 4.17).

4.100 Deliberate self-harm is a very common reason for presentation to departments and as noted above there is a wide range of mental health problems associated with this presentation. It is important that as many users are offered psychosocial assessment and where necessary support. Misuse of alcohol and drugs is common within the deliberate self-harm group and while brief counselling can be undertaken in an A&E setting, it is important that there is ready access to addiction services.

4.101 It is again important that comfortable, confidential and safe accommodation is provided for interviewing in the A&E environment. In view of the potential for aggression there should be clear policies including support procedures by security staff.

4.102 Young people attending A&E with mental health problems should be seen by those with appropriate expertise. Clear protocols authorising responsibility (based on relevant expertise) should be in place between Liaison Teams and CAMHS teams.

4.103 **Commissioning and Audit of Service.** The above services should be developed in all general hospitals throughout Northern Ireland, the extent depending upon the size of the hospital and particular patient mix. Specialist hospitals may require emergency liaison mental health assessments and local arrangements should be established for each hospital. This should be part of the commissioning process although LMHS teams may not be required at these hospitals.

Recommendations

54. Appropriate education should be provided to general hospital staff:
    - to prevent people with mental health needs feeling stigmatised
    - to provide basic psychosocial assessments and support.

55. Acute hospitals should ensure that appropriate liaison services are established:
    - clear referral protocols should be in place
    - general ward staff should, where necessary, have access to appropriately trained and experienced mental health professionals on a 24 hour basis
    - Liaison Services should provide prompt same day assessment and advice on therapeutic interventions, risk management and follow-up.
    - confidential, comfortable and safe accommodation must be provided to interview service users in A&E environments and general hospital settings. Policies outlining the support procedures from security staff should be established.

56. Liaison Services must be able to access addiction services promptly for service users willing to avail of them.

57. Liaison Services to A&E departments should be appropriate for user needs:
    - all people with deliberate self-harm should be offered psychosocial assessment and appropriate after care plans
    - people with problems relating to addiction attending A&E should be able to avail of prompt access to community addiction services
    - young people attending A&E with mental health problems should be seen by those with appropriate expertise. Clear protocols should be in place between Liaison Teams and CAMHs teams.

Therapeutic Interventions

(i) General

4.104 From a health perspective services, their configuration and organisation, are but vehicles to promote recovery and underpin optimal delivery of specific therapeutic interventions, care and support. Service users with more complex and severe mental disorders often have enduring or intermittent problems including residual symptoms, functional impairments and disabilities affecting their role and functions within their family, work and wider social situation.

4.105 The variety of needs require a range of skills, including self help skills, and understanding grounded in evidence-based health and social care, including evidence based processes of care provision.[95] This in turn assumes the availability of an appropriately trained and adequately staffed workforce (see Chapter 7). Service user participation in service delivery can make a significant contribution to both the values base and the effectiveness of services.

4.106 Evidence, including strong and consistent user consultant responses to the Review, directs attention to the importance of the service user/professional relationship. This is a key element in the recovery process and for all therapeutic work. Optimal holistic therapeutic interventions and care depend fundamentally on collaborative working between persons with mental health needs, their families, carers and the professionals and organisations involved. In addition to specific intervention skills, health and social care professionals require a range of general skills including interpersonal skills, team-working and communication skills.

4.107 **Psychological Therapies**. One of the consistent observations received by the Review is the relatively poor development of psychological therapies in Northern Ireland, resulting in limited access and unacceptability long waiting lists for assessment and treatment.[96] There must be improved access to psychological therapies, from appropriately trained, qualified and supervised staff.[97]

4.108 A number of service examples for the delivery of psychological therapy are in operation within the NHS, for example the Northumberland Tiered Approach.[98] Their aim is to increase access to a broad spectrum of psychological therapies for a range of problem severity and complexity. Services place emphasis on training and supervision as well as the provision of intensive and dedicated therapy services. These can probably be best provided through a Trust-wide multi-professional department.
Good Practice Example (Annex 5.4.7)

(ii) Treatments and Interventions

4.109 The complexities of mental illness and their sequalae often require a variety of approaches – medication, psychological therapy, psychosocial interventions and specific social and occupational programmes such as vocational training. Recent developments in models of service delivery, psychological and social interventions suggest that the range of therapeutic options is likely to expand significantly.

a. Use of Medication

4.110 Medication is an important aspect of therapeutic interventions for specific mental health disorders. The most up to date evidence based guidelines such as those of the British Association of Psychopharmacology and the National Institute for Clinical Excellence (NICE) should be employed and the medication should be within the recommended dose ranges stated in the British National Formulary. Medication can be an important part of a comprehensive care package which addresses an individual's clinical, emotional and social needs.[99-103, 105-117] The choice of treatment intervention should be made jointly by the individual, the clinician responsible for treatment, and where appropriate the individual's [101] carer or advocate. [104]

b. Psychological Interventions

4.111 Major advances in psychological treatments have taken place in the last few decades, both in terms of their sophistication and proliferation. In parallel, a more rigorous approach to researching clinical effectiveness has resulted in a number of reports advising which psychological therapies may be helpful for particular conditions. [118,119,120] The evidence is now strong in relation to the effectiveness of specific psychological therapies for anxiety disorders with marked symptomatic anxiety (panic disorder, social phobia, obsessional compulsive disorder and generalised anxiety disorder). [120] Likewise, rigorous protocols have been developed for post traumatic stress disorder and moderate levels of depression.[120] A report from NICE clarifies the state of the evidence in relation to psychological approaches to the treatment of eating disorders.

4.112 Evidence about the efficacy of psychological approaches with people who have severe and enduring mental illness is relatively recent and it may suffer from a bias that affects all research on such treatments. [122-144] Certain treatments, because they can be protocol driven (such as cognitive behaviour therapy (CBT)) lend themselves to investigation through randomised controlled trials, whilst others such as the psychodynamic therapies do not. This may result in some treatments being assigned an artificially low grade of evidence.

4.113 Increased knowledge about the interaction of biological, psychological and social factors involved in psychosis, the "stress-vulnerability" model [121] has led to a multi-factorial understanding of risk and relapse in psychosis. This model suggests that each of us has a different level of vulnerability to the development of psychotic experience. The vulnerability may be the result of biological factors (e.g. genetic, or birth trauma) or psychosocial ones (e.g. resilience to stress or history of childhood abuse or neglect). This model underpins and provides a rationale for psychological and social interventions. For example, it hypothesises that if an individual is provided with increased resources for coping with stress, or reduce the stress in the environment, significant advances in outcome could be made.

4.114 Access to Psychological Interventions. Accessibility to psychological interventions remains extremely poor within Northern Ireland. Increasing accessibility to evidence-based interventions for psychosis is a major challenge involving a number of elements. This includes staff training.

4.115 **Staff Training**. There is a requirement for training across all mental health professional groups in developing skills of therapeutic relationship building and the use of evidenced-based psychosocial therapies. [124]
Good Practice Examples (Annex 5.4.8)

Recommendations

58. The choice of therapeutic interventions should be made jointly by the individual and the clinician responsible for treatment.

59. Medication, psychological and social interventions must be integrated within a complete package of treatment, care and support.

60. Therapeutic interventions must be provided within a multidisciplinary framework, according to evidence-based guidelines.

61. Psychological therapy services must be organised in ways that promote the use of psychological interventions in routine practice.

62. A workforce strategy developing psychological therapy services must be addressed as a matter of urgency.

63. A Northern Ireland-wide training strategy to improve access to psychological therapies and psychosocial interventions must be developed as a matter of priority.

PHYSICAL HEALTH

4.116 People with mental health problems are at increased risk of having physical health problems. Many of the excess deaths of people with more complex and enduring mental disorder are potentially preventable by better medical treatment and attention to lifestyle, including diet and smoking. Smoking as substance use is part of the specific Review of Alcohol and Substance Misuse. Assessment, therefore, should cover physical health needs. One approach to identifying and targeting people with more severe and enduring mental health needs is the establishment of case registers at primary care level.[145] Primary and secondary care services, in conjunction with the service user, should jointly identify which service will take responsibility for monitoring physical health.

4.117 General Practitioners should consider the health promotion of people with severe mental health problems within their practice and regularly monitor their physical health. The NICE Guidelines for Schizophrenia recommend paying particular attention to endocrine disorders such as diabetes and hyperprolactanaemia, cardiovascular risk factors, side-effects of medication and lifestyle factors such as smoking.[19]

Recommendations

64. The assessment of people with more complex mental health needs must include assessment of physical health needs. Local providers of services should agree which service (primary or secondary) will take responsibility for monitoring physical health.

65. Registers should be established of people with severe mental health needs at primary care level.

Configuration of Person-Centred Services

4.118 The goal of the whole system of care is to provide person-centred services for a wide range of needs. All provider units should aim to have the main elements of service provision (above) in place and operational by 2010. Organisational structures play a key role in effective and efficient delivery of services. While the details of service configuration must be informed by the local context the following is presented as a model of good practice. The following key elements must be supported by the full range of service elements with optimal functioning interfaces with other services eg forensic services, child and adolescent services.

4.119 **A Model Service Configuration**. As noted earlier, the Review recommends provider units serving populations of between 200,000 and 300,000. Provider unit service configuration is here considered for a community of 250,000 people. The short-term community staffing goal for this population is 150 (see 4.20) with appropriate training including staff required for Home Treatment and Assertive Community Treatment. As service providers advance towards their goals of a comprehensive person-centred service the following configuration of the key building blocks of provision are recommended, based on present evidence and on the principles informing the Strategic Framework.

4.120 **CMHTs Supporting Primary Care**. Present evidence suggests that the optimal model of CMHT configuration is 5 teams, each of approximately 11 staff, supporting primary care services, each servicing a population of approximately 50,000 (see Figure). Teams will require access to a comprehensive range of community resources, both statutory and independent sector. Such teams should provide Tier 2 level services for deaf people with mental health problems and women with perinatal mental health needs. Where a provider unit has a general hospital within its catchment then one of the local CMHTs should have close links with the Liaison Mental Health Services. Teams must have a multidisciplinary ethos (nursing, social work, psychology, medical) in order to provide a broad range of skills and therapeutic interventions. Teams should have user membership, engaged through appropriate employment arrangements.

4.121 **Recovery Service CMHTs**. Sectorised services are required for people with enduring and recurring mental disorder. Three CMHTs are recommended, one each underpinning Recovery Services for approximately 85,000 people (see Figure). As a short-term goal, the staff complement for each team should be approximately 23 with a multidisciplinary composition appropriate for the needs of recovery services including nursing, social work, occupational therapy, speech therapy, physiotherapy, medical and user participation. These CMHTs will be required to provide Tier 2 level services for the mental health needs of people with brain disease and injury, ASD, also services for people with challenging behaviour, dual diagnosis, first episode of psychosis and mild learning disability. HT and Assertive Community Treatment teams should be closely associated with each Recovery CMHT.

4.122 **Home Treatment Teams**. In order that HT teams can provide 24/7 services, it is recommended that the complement for a provider for 250,000 should be 24 staff, configured as three teams of 8 staff, each team linked with a Recovery

CMHT. Close association between each HT team and CMHT is essential to enable HT teams fulfil their gatekeeping function and ensure continuity of care between Recovery CMHTs and inpatient services. In order to ensure out of hours services, HT teams will need to co-operate across the Provider Unit. Five staff working in Assertive Community Treatment should be linked to each Recovery CMHT. A home-based approach to community service provision is recommended as the long-term goal of Recovery services. This is dependent on adequate staffing and can be linked to a convergence of the roles of HT teams, ACTs and Recovery CMHTs.

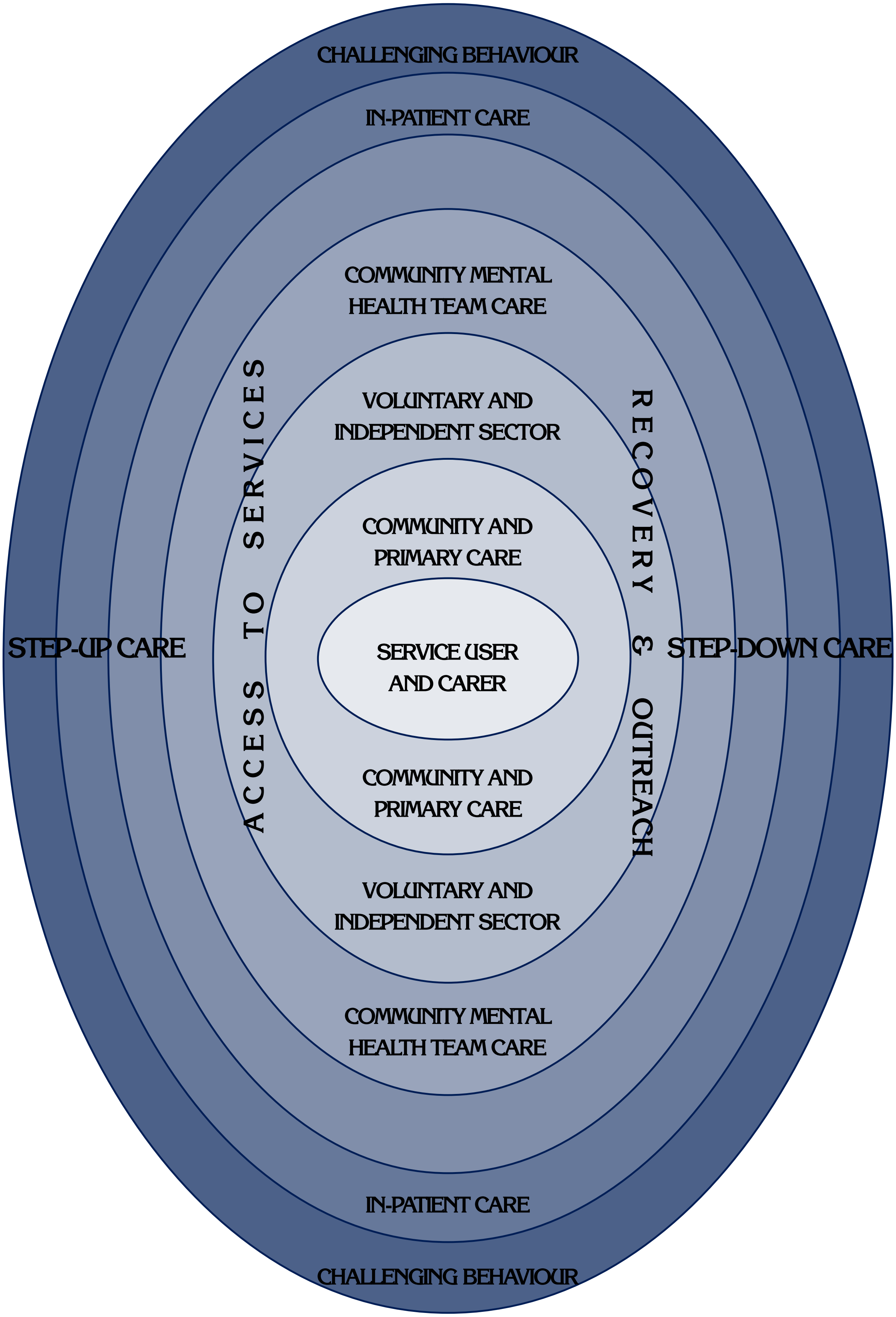
4.123 **Psychological Therapy Services**. Psychological therapy services should be consolidated into a single unit from which support, supervision and training can be provided for all CMHT staff. They should be responsible for specialist services for people with psychological trauma, people with eating disorders and people with personality disorders.

4.124 **Inpatient Provision**. Acute inpatient services should be provided as part of an integrated model of crisis services with locally accessible units, utilising where possible, the facilities of general hospitals. Acute inpatient services can be complemented by step-up and step-down houses in close collaboration with HT teams (see Figure). As the goals of the Strategic Framework are achieved, then the requirement for acute inpatient provision should reduce to approximately 20 places per 100,000, their location recognising the advantages of general hospital settings.

4.125 In addition, inpatient facilities for people with challenging behaviour with approximately 25 places for a population of 250,000 people will be required. The requirements for inpatient provision will turn critically on the adequacy and comprehensiveness of alternative community provision, including residential facilities.

4.126 The model is predicated on all of the services elements specified above for secondary services, including the skill levels of staff, being successfully implemented to high fidelity with the recommendations. Monitoring and evaluation of this implementation will, therefore, be essential.

The Whole System of Care



CHAPTER 5

SECONDARY MENTAL HEALTH SERVICES - PART II

INTRODUCTION

5.1 A person-centred approach is core to the vision of the Strategic Framework and, as noted in Chapter 4, services must reflect the multi-dimensional nature of user and carer needs. While the primary focus of the last chapter was on health and social care services reform, we must now consider a range of other issues – education; training; occupation; accommodation; income; advocacy; personal life; family life and culture; and carer and family needs.

EDUCATION, TRAINING, OCCUPATION

5.2 Occupation, defined as all purposeful human activity, encompasses personal activities of daily living, leisure activities and work activity. Education and training relates to activities compatible with both vocational outcomes and personal development. Occupation is a basic human need, which is directly related to the meaning and quality of ones life[1] and important for both physical and mental well-being. Everyday occupations play a significant part in maintaining structure, meaning and social inclusion.

5.3 Serious mental illness often results in a disruption of occupational balance, with lack of meaningful occupation limiting social connections and increasing stress and isolation.[2] In quality of life studies, service users report lack of a job, loneliness, health problems, looking after self and lack of leisure activities as priority areas in relation to quality of life.[3, 4, 5] The Labour Force Survey of 2002 Great Britain found that only 21% of adults with mental illness were in employment.[6] Three issues are important for the Strategic Framework - assessment, barriers to employment and employment models.

Assessment

5.4 Recent clinical guidelines emphasise the importance of holistic assessment including social functioning, occupational status and potential, with interventions beginning at the earliest opportunity. The importance of assistance to access employment, education and training opportunities has been acknowledged.[7] Supported employment programmes are but one aspect of work activity which should be made available. Interventions aimed at maintaining and improving social networks through appropriate day care programmes should be available to all service users.[8]

5.5 The Mental Health Policy Implementation Guidance advises that the availability of specialised employment, education and occupation services should be a priority for all those with severe mental health needs. Trained professionals with the skills to assess these areas should be available to all community mental health teams. With respect to early intervention for psychosis the guidance is that all users should have a vocational assessment within three months of referral to the service.[9]

Barriers to Return to Work

5.6 Many people with enduring mental health problems are financially better off if they remain unemployed and in receipt of social security benefits. Current rules and financial incentives to move from benefit to work are complex, fragmented and assume a move from no work to full-time work. For those on Incapacity Benefit, work is allowed in specific circumstances. Even with the support of Disablement Employment Advisors and professional staff the process can be complicated and daunting.[10]

5.7 The Department for Work and Pensions has recognised these difficulties and produced new proposals to address some of the issues. The proposals emphasise rehabilitation and job retention. Specialist help will only be effective provided there are closer working relationships between DHSSPS, Department of Enterprise, Trade and Investment (DETI), Department of Employment and Learning (DEL), Department of Education (DE), Department of Social Development (DSD), healthcare providers, the voluntary sector and employers.[11]

Employment Models

5.8 The following are models of employment, which encompass the range of provision from social support through to health care and to those concerned with productivity.[12] With the exception of Clubhouse, all of these options exist in Northern Ireland.

Vocational rehabilitation
(Prevocational skills training)
Sheltered employment
Clubhouse
Voluntary work

PACT (Placement, Assessment and
Counselling Team)
Transitional employment
Supported employment
Social firms/ businesses

5.9 The paucity of quality research in this area could lead to a narrow view of those services which represent 'best practice'. While a Cochrane review concluded that "supported employment is more effective than prevocational training in helping severely mentally ill people to obtain employment."[13], it must be noted that there is a tendency to select more able individuals for supported work placements. Most of the studies reviewed were conducted in America, where the social security systems are less extensive than in the UK.

5.10 Two features of employment programmes that have most empirical support are: integration of mental health and vocational services within a single service team; and the avoidance of pre-placement training.[14] People with complex mental health problems should be offered choice in terms of occupational, education and training opportunities, facilitating service users to experience a meaningful day and consequently improving quality of life. Emphasis should be placed on user-focused initiatives that allow a progression towards paid employment where this is the most appropriate option for the client. A range of occupational services should be provided within each Trust area to allow professionals and service users to match the level of need with the service provided. The continuum should include:

services with a predominantly treatment function

leisure and creative activities

good quality vocational guidance

specialist day care

high quality sheltered workshops

links to learning and training opportunities and voluntary work

social enterprises

access to supported placements in competitive employment.

5.11 The use of mainstream community services, facilities and activities should promote social inclusion and help reduce the stigma that mental health service users face. Effective links to voluntary work and organisations such as Further Education Colleges, Educational Guidance Service for Adults and the various job brokers and training organisations will expand the opportunities for people with complex mental health needs.

5.12 Some service users require considerable support in order to access mainstream services. Supported education initiatives for employment or leisure services have been shown to be effective in relation to health gains for people with more enduring mental health needs.[15] The key worker should retain a co-ordinating role for the client[16]. Service providers, particularly those with a mental health remit, should be exemplary in providing and promoting employment opportunities for service users. Sensitive, needs-led, flexible support must be maintained to reduce anxiety and alleviate barriers to engagement.[17]

5.13 Significant benefits of volunteering have been observed for those with mental health problems.[18] For those service users with complex and enduring mental health needs adequate support and tailoring of opportunities must be provided in order to maximise the benefit from volunteering.

5.14 Leisure as an occupation contributes to social identity and is fundamental to physical, social and psychological well-being. For many service users successful engagement in leisure activities can be a catalyst towards employment. For others it can be the predominant occupation that defines their identity and maintains social inclusion. At all levels, leisure occupation should be valued and facilitated by mental health workers.
Good Practice Examples (Annex 5.5.1)

5.15 Assessment of an individual's occupational performance, exploration of vocational goals and networking with local service providers is currently being performed by many CMHTs within Northern Ireland. However, many teams do not have access to Occupational Therapist (OT) expertise or, when present in teams, they are engaged in generic work due to high caseload numbers amongst multidisciplinary team members. The 'Avon' model (Annex 5.5.1) could be replicated in Northern Ireland. The interventions required are core skills of OTs and partnership working is already established in many Trusts.

Recommendations

66. People with severe mental health needs should be offered an early opportunity to participate in a full occupational assessment. This should be reviewed on an annual basis as part of the service user's review. Assessment should be conducted by an OT with the emphasis on quality of life, time management and occupational issues.

67. More straightforward and flexible social security benefits should be introduced to facilitate the transition from benefits to work.

68. A comprehensive range of occupational services must be provided within each Trust area and should include access to voluntary work, educational and leisure opportunities.

69. Day care services should provide a comprehensive range of activities and opportunities to support the different needs of service users.

70. Vocational specialists with mental health expertise and the flexibility to work on an interagency basis should be commissioned to enhance the rehabilitative function of CMHTs.

ACCOMMODATION

5.16 Having a home is a basic human right. The impact of poor housing on mental health has been well documented, as has the association between type of housing and prevalence of mental health problems. The Audit Commission 1994 found that:

- poor housing is particularly common among people with mental health problems;
- mental disorder is a frequent cause of tenancy problems and tenancy breakdowns; and
- poor housing and inappropriate accommodation can lead to the development or exacerbation of mental health problems.

5.17 Suitable accommodation is a fundamental element of effective services to support people with mental health problems. A number of principles need to be considered in order to ensure an appropriate range of accommodation and support. These principles draw mainly on the recommendations of the Newby Inquiry:[19]

- as far as possible, people with mental health problems should have a choice of the type of accommodation in which they wish to live. This has to be balanced in relation to the degree of risk posed to themselves or others;
- assessment of accommodation needs should be a component of an overall assessment;
- support for people receiving mental health services should be available to people with mental health problems regardless of where they are accommodated; and

- providers of accommodation should receive training and should be supported regardless of whether the accommodation is statutory, voluntary or private.

5.18 Supporting individuals in suitable housing in ordinary settings will help them gain access to a wide range of mainstream services and resources. The challenge is to provide accommodation with support for the range of needs experienced by those with mental health problems without recreating institutions.

5.19 Homeless and rough sleepers present particular challenges. A recent study in Belfast identified mental health problems among 86% of single homeless people.[20]

5.20 The Northern Ireland Housing Executive, through joint planning arrangements with the Health and Personal Social Services, seeks to extend the supported housing option for various client groups in response to discharge from hospital and wider community needs. Each year 20% of the new build programme is targeted to meet supported housing needs.[21]

Accommodation Needs

5.21 People with mental health needs have a range of accommodation requirements. The foundations of good provision include quality of care and management. Accommodation needs range from independent tenancies in mainstream housing to 24 hour intensively supported accommodation. A key objective of People First: Community Care in Northern Ireland for the 1990's was to promote the development of domiciliary day and respite services to enable people to live in their own homes, whenever possible.

Types of Supported Housing

5.22 Supported housing involves providing integrated housing and support. The type of housing available covers a wide range including:

- temporary or homeless hostels: shared housing where board or access to cooking facilities are provided;
- rehabilitative supported housing: shared housing in group homes or hostels providing a rehabilitation service;
- shared supported housing accommodation in shared housing or flats providing a permanent home;

- self contained supported houses: housing provided in flats or houses, which is not shared with others but has targeted integrated support; and
- residential care homes: usually shared accommodation, which are registered under the Registered Homes (Northern Ireland) Order 1992 (since April 2003 many of the registered care homes in Northern Ireland managed by the voluntary sector and the statutory sector with special provision for people with mental health needs have de-registered and now operate under Supporting People).

5.23 People who require support to stay in their own or rented accommodation may require essential support at a practical level to ensure the maintenance of the tenancy, e.g. floating support, home help, mental health support workers. Those who need respite on a short stay basis to prevent acute admission may require emergency or non-emergency respite. Non-emergency respite may be required to accommodate people whose mental health is deteriorating and who require input from experienced staff over a period. Examples of this provision is available mainly in statutory/non hospital facilities in Northern Ireland.
Good Practice Example (Annex 5.5.2)

5.24 Crisis diversion/non-hospital accommodation may be provided as part of Crisis Response to prevent inappropriate admission to hospital.
Good Practice Example (Annex 5.5.3)

5.25 People who are returning to independent living as part of their rehabilitation require specialist accommodation with support. They should, as far as possible, have choice of location. Moving out of an institutional setting to independence can be daunting. Many will require phased independence combining suitable accommodation and daytime occupation. Staff in supported housing can provide valuable help to those who lack social skills. This can be enhanced by access to daytime occupation and leisure facilities. Confidence building is important and input is required from trained and experienced staff.
Good Practice Example (Annex 5.5.4)

5.26 People with challenging behaviour require specialist facilities with high staffing levels (see 4.63). This accommodation may be provided by the Housing Executive or Housing Associations in conjunction with Trusts or voluntary sector. It may also be provided through therapeutic type communities. It is important that the layout of the accommodation provides adequate personal space and access to daytime occupations and intensive staff support. Staff

require specialist training in relation to dealing with challenging behaviour and potential violence. Risk assessment should be carried out to identify patterns of behaviour, which may lead to harm either to the resident or others. Thorough risk assessment and risk management are essential to allow an acceptable level of freedom and independence for personal development within a context of safety for both service users and staff.
Good Practice Example (Annex 5.5.5)

5.27 People with mental health problems without accommodation pose a particular challenge. Homelessness may have been caused or exacerbated by their mental health problems. Some may have become displaced because of their mental health problems or rejected from accommodation as a result of their health problems or the degree of challenge posed to staff. Many have dual diagnosis. (See 4.74)

5.28 It is essential that homeless people with mental health problems have access to mainstream services at primary and secondary care level. Accident and Emergency Services provide an important access point to care. Good communication between generic and mental health services is essential.
Good Practice Examples (Annex 5.5.6)

5.29 Access to housing alone is not sufficient and must be complemented by the provision of appropriate therapeutic interventions and support, for example using Assertive Community Treatment [22] (see 4.46).
Good Practice Example (Annex 5.5.7)

5.30 The Homeless Strategy and Service Review Northern Ireland Housing Executive 2001 aims to reduce the levels of homelessness by the provision of a tenancy support service and by developing move on accommodation as part of their supported housing programme.

5.31 Discharge protocols in mental health services in Northern Ireland require further refinement to ensure that people leaving mental health facilities have appropriate accommodation on discharge. Close co-operation is required between housing, mental health services and the independent sector.

Recommendations

71. Providers should ensure that a complete range of accommodation is available to meet the needs of people with mental health problems. Supporting People partnership between Trusts, Boards, Northern Ireland Housing Executive and the independent sector should be sufficiently flexible to make timely responses to the accommodation needs of people with mental health problems.

72. Service users should have choice of accommodation appropriate to their needs and given maximum independence through appropriate levels of support. Care environments and practices should be designed to maximise personal autonomy and reduce the risks of institutionalisation. Service principles must underpin the development of standards and must focus on the needs and rights of individuals.

73. Discharge protocols should ensure that people leaving mental health facilities have appropriate accommodation.

74. Staff working in residential settings should have adequate support and training including, where appropriate, training in the management of people with challenging behaviour.

75. Statutory services should provide support to residents and staff to optimise community living, prevent unnecessary hospital admission and to reduce the risk of homelessness in people with mental health needs.

76. Monitoring and evaluation of services should be a continuous process and involve users and carers.

SOCIAL SECURITY BENEFITS AND SUPPORT

5.32 In the non-disabled population in the UK, 15% of people are economically inactive compared to around half of the disabled population. The figure for people with mental health difficulties is around 80%.[23] In Northern Ireland, more than a third of Incapacity Benefit claimants have a mental or behavioural disorder. In November 2002, over 37,000 people were in receipt of Incapacity Benefit as a result of mental and behavioural disorders and just under one in five people receiving Disability Living Allowance cited mental health problems as their main disabling condition.[24]

5.33 The key issues facing people with mental health problems are:

- inadequate levels of benefit, for example, personal expenses payments for people in residential/institutional care, help with the cost of prescriptions, problems with the Social Fund;
- assessment – the prevalence of medical examinations that are often seen as intimidating; many of those conducting assessments have limited experience of mental illness;
- easing the transition to work; there is much of a gap between incapacity and getting back to work. The current rules and financial incentives to move from benefit to work are complex and fragmented and there is a need for simpler, more flexible and improved financial incentives to allow people to return to work without the fear of penalties if unsuccessful; and
- delivery – there is a need to take greater account of mental health issues in the administration of social security benefits. Awareness training, increased user involvement in training and planning, improved claim forms and tailored independent advice and advocacy services are all needed.

Levels of Benefit

5.34 While considerable effort has been made to improve the level of financial assistance available to families (both in and out of work) and older people, Incapacity Benefit for a single person unable to work because of ill-health or disability is worth barely one sixth of average earnings. The weekly rate of Income Support based Jobseeker's Allowance for a single person is presently (2004) £55 if aged 25 or over and £44 if under 25.

5.35 Young single people's difficulties are compounded by private rented sector housing benefit rules which apply a 'single room rent' rule to entitlement. Many young single people with mental health problems fall foul of this rule and get into difficulties paying rent. Young people, therefore, find themselves pushed towards less self-contained, cheaper accommodation which may not be appropriate. An exemption to the single room rent should be made for people with mental health difficulties.

5.36 Social Fund rules make it difficult for single people to qualify for grants for essential items such as furniture or household equipment. Often, the only option is a loan which compounds financial difficulties. The Social Fund should be reviewed so that loans do not continue to be the main form of discretionary support.

5.37 Income Support for people in residential care or other institutional settings currently (2004) entails paying a personal allowance of £17.50 a week to meet living expenses. This can lead to difficulties in managing the transition to independence.

5.38 Prescription charges can be a major cost to people with ongoing health problems. Often, people with long-term mental health problems on incapacity benefit alone do not qualify for help with prescriptions. Pre-payment certificates allowing multiple and long-term prescriptions to be paid in advance are helpful but are often beyond the means of people on low incomes. People with severe mental health problems should be exempt from such charges.

Assessment

5.39 The current strategy for Social Security is 'work for those who can, security for those who cannot'. As a result, a considerable effort has been put into encouraging the long term sick and disabled back into work.* However, there is a need to recognise that not everyone is capable of open employment (going beyond those granted an automatic exemption from these arrangements). It is important that all frontline employment advisers receive mental health awareness training, part of which should involve interaction with people directly affected by mental ill health.

5.40 The current strategy also contains an element of compulsion. People on Incapacity Benefit who fail to attend interviews can be penalised by loss of benefit or incapacity status. This fails to acknowledge the pressure having to attend such interviews can cause for someone with a severe mental illness.

5.41 Medical assessment is a regular feature of establishing and retaining entitlement to key disability benefits (notably Incapacity Benefit and Disability Living Allowance) and the quality of such assessments has been subject to significant scrutiny.[25] Rushed assessments, lack of knowledge of mental ill-health, disbelief of claimants, a disregard of specialist evidence and cultural insensitivity are not uncommon experiences. A report on the Social Security Agency's Medical Referee Service by the Advice Services Alliance in 2002 was also critical of the quality of assessment and sensitivity of some doctors.[26] The Social Security Agency (Northern Ireland) has recently announced a review of the Medical Referee Service. This could usefully lead to greater use of occupational nurses and mental health specialists (medical and non-medical).

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* For example, the introduction of Jobcentre Plus, compulsory work centred interviews for new and recent incapacity benefit claimants, the New Deal for Disabled People initiative and tax credit and benefit reforms aimed at easing transition back to work.

Easing the Transition to Work

5.42 People with mental health problems who have been on benefit for long periods often need intensive support to get back to work. The current Social Security system does not allow for a continuum that would enable a person to move gradually through voluntary work to part time work and full time work or to stay at one level for a prolonged period if appropriate. The Government has improved flexibility within the social security system to encourage a return to work, but the current arrangements are complex, fragmented and not easily understood by claimants. An understanding of the arrangements requires extensive knowledge of social security and concerns have been raised that a move into training or work triggers a review on the assumption that a person's condition has improved. This is a disincentive to rehabilitation through work or training.

5.43 Improvements have been made to claim forms in recent years, but there is a considerable way to go. The claim form for Disability Living Allowance remains complex and significantly oriented towards physical impairments. The claim form for incapacity benefit has an open question about mental health with no guidance as to the information required.

5.44 The Social Security Agency is moving towards providing greater support to assist with claims for disability benefits. It has also worked with the voluntary sector to look at ways of enhancing its customer service to particular groups (for example, physically disabled people and ethnic minorities). A similar exercise working with voluntary sector and other interested parties to examine customer service issues for people with mental health problems would be a welcome development.

5.45 There is a need to ensure that all those involved in frontline benefit administration and decision-making receive mental health awareness training that incorporates interaction with people with mental health problems. This also applies to the Medical Referee Service personnel, as well as chairpersons and panel members hearing social security appeals. People with mental health problems should have access to an independent dedicated advice and advocacy service to deal with social security problems.

5.46 The social security system should support and enable people with mental health problems to live independently with dignity and a good quality of life, both in and out of work.

Recommendations

77. The Social Fund should be reviewed with a view to ending loans as the main form of discretionary financial support. An exemption to the single room rent should be made for people with mental health difficulties. People with severe mental health problems should be exempt from prescription charges.

78. Trusts must ensure that people with mental health problems have access to independent dedicated advice and advocacy services to provide assistance in dealing with social security problems.

79. Returning to work: people with mental health problems wishing to work and who have been on benefit for long periods should be provided, as necessary, with intensive support. Rules encouraging a return to work should be made more flexible and easier to understand.

80. Staff Training and Development. All frontline benefit advisers, social security decision-makers, medical referee service staff and appeal tribunal members should receive mental health awareness training, part of which should involve interaction with people directly affected by mental ill-health. Medical assessors must have appropriate skills in assessing the mental health needs of applicants. Consideration should be given to greater use of mental health specialists (medical and non-medical).

PERSONAL LIFE, FAMILY LIFE AND CULTURE

5.47 Mental well-being has been defined as the emotional and spiritual resilience which enables us to survive pain, disappointment and sadness. It is a positive sense of well-being and an underlying belief in our own and other dignity and worth.[27]

Social Self

5.48 A person's social connectedness – activities, relationships, interests, networks – has a significant impact on mental well-being and self-esteem. The reactions of others are often influenced in our social life, our activities, interactions, our social self. Becoming mentally unwell can profoundly affect both our own social interactions and the reactions of others. It is in such situations that the experience of ignorance, fear and stigma can bring a new dimension of distress to the sufferer.

5.49 Mental ill-health and the accompanying distress can affect all aspects of one's social life and relationships - within the family, with friends, with work colleagues. The sense of feeling isolated and stigmatised is a very real experience of many sufferers. There is also a sense of disempowerment and the distress arising from this – "my life will never be the same again". Acknowledgement of these issues and concerns can be of particular importance in promotion of recovery and needs to be recognised by professionals.

Relationship between Service User and Professionals

5.50 The relationship between service providers and service users is of considerable importance in building and maintaining self-esteem, hope and self-worth for individuals with severe episodes of mental illness, experiencing loss of insight, loss of control, in addition to the painful experience of the symptoms of mental illness. This relationship can also provide a role model for family members who themselves may be bewildered and distressed through the experience of an illness episode. The engagement and empowerment of family members can greatly assist in the recovery and re-engagement of the service user in their social life and relationships.

Sharing of Information

5.51 From a service user perspective, knowing that the professional to whom you are relating is trustworthy, will listen in a non-judgemental way and respects user views and requests, is essential to a partnership of trust, respect and empowerment. Confidentiality is an important part of this relationship. However, if a service user asks a family member or friend to request information on his/her behalf, this request should be respected by professional staff. Once a delegated person has been named and the request confirmed by the user of the service requested, information should be given to the nominated person. This need not include personal information.

5.52 Access to information has generally been experienced as a problem for service users in mental health services. It is often difficult to get clear information and this lack of clarity is a problem for users, family and friends. The failure to convey relevant information clearly and in simple terms can cause distress to the user and their families. Information is required about services, choice of services, specific interventions including, for example, medication side-effects and crisis arrangements.

5.53 In the situation of involuntary admission, clarity takes on even greater importance. The sufferer in such situations often experiences a significant intrusion into their personal and family privacy. Involuntary admission procedures should be clearly explained and all involved should identify themselves to the sufferer, family and friends. Difficulties for the user in understanding information at such times requires professionals to pay even greater attention to communication and information sharing.

Spirituality

5.54 Within a multi-cultural society, the service user's specific cultural, spiritual and religious needs need to be recognised and acknowledged. With the emphasis on community based care and treatment, the religious and spiritual dimension of an individual's life should be considered as part of holistic assessment.

5.55 From a user perspective, spirituality can be an important part of one's personal life and in times of crisis a major source of sustenance. This can be of particular importance in situations where admission to hospital is required with the inevitable separation from family, friends and one's local community. It is a common user experience when in hospital, that religious and spiritual needs are not adequately met. Service providers need to be sensitive to the spiritual needs of service users at such times.

Culture

5.56 Culture shapes many aspects of mental health and people from ethnic minority communities have needs and concerns related to their cultural uniqueness, their minority position and often issues related to recent immigrant status. Culture shapes both perception and expression of mental distress and disorder. It also influences attitudes and coping mechanisms for the person, the family and for the specific cultural group. Ethnic minorities are especially vulnerable to stigmatisation, discrimination, racial stereotyping and social isolation. Many of these issues have been highlighted in the recent user survey of ethnic minorities in Northern Ireland.[28]

5.57 Mental health services must be sensitive to these issues and to the particular needs of ethnic minorities. The Department of Health report "Inside Outside"[29] emphasises three key objectives:

- to reduce and eliminate ethnic inequalities in mental health service experience and outcome;
- to develop cultural capability of mental health services; and

- to engage the community and build capacity through community development workers.

5.58 Important factors are personal attitude, professional skills and competencies, and awareness and appraisal of specific cultural norms. These point to important aspects of professional development among mental health professionals. Priority must also be given to the provision of better information and better communication including the appropriate use of interpreters and translators.

Recommendations

81. Information. Service users and, where appropriate, carers, family and friends should be provided with relevant information in clear and simple terms. The information and communication needs of service users in situations of non-voluntary admission require special attention. Priority must be given to improved methods of communication and information for people from ethnic minorities, including the use of interpreters and translators.

82. Services must be sensitive to the cultural needs of people from ethnic minority communities. Within a multi-cultural society, the service user's specific communication, cultural, spiritual and religious needs must be recognised and acknowledged.

83. Advocacy services should be sensitive and appropriate for the needs of people from ethnic minority communities.

84. Staff training and awareness. The distress accompanying mental illness and its impact on an individual's personal life, including a sense of stigma, need to be recognised and acknowledged by mental health professionals. The importance of the relationship between service providers and service users in the maintenance of self-esteem, hope and self-worth needs to be recognised and valued by providers.

ADVOCACY

5.59 In 1996 Building Bridges[30] identified service user involvement as a fundamental principle in mental health care and user advocacy as an important support of this process. The Mental Health Patient's Charter[31] states that service users should be informed of and have access to local advocacy services. The purpose of advocacy is to ensure maximum preservation of each service user's personal autonomy and self determination.[32] Advocacy assists service users in expressing their views and taking an active part in decision making affecting their situation. The United Kingdom Advocacy Network (UKAN) stresses that a key objective of advocacy is to enable people to advocate for themselves. Nevertheless, there are occasions when people are unable to represent their own views and interests.

5.60 Peer advocacy is particularly valued by service users. It challenges the discrimination and stigma attached to mental illness. It is a process for empowerment by which to build or rebuild well-being for people whose mental health condition has damaged self-esteem and confidence.[33]

5.61 The Review considers advocacy as an essential part of mental health services and expects the issue to be taken forward by the Legal Issues Expert Working Group.

Good Practice Example (Annex 5.5.8)

Recommendations

85. Independent Advocacy services ensuring maximum preservation of each service users personal autonomy and self determination must be established in all Trusts providing mental health services.

86. Advocates should be involved in service planning and development, be given access to appropriate service information and receive support, as necessary, from Trust staff.

CARER AND FAMILY NEEDS

5.62 The UK Government's National Strategy report 'Caring about Carers'[34] states that

- Northern Ireland has 250,000 carers, 7% (17,500) of whom are caring for a person with mental health needs and a further 15% (37,500) for someone with both a mental and physical disability;
- carers need support and information, especially when caring for someone with a mental health problem;
- nearly 60% of carers receive no regular support from service providers;
- stress related health problems are most acute among carers of people with a chronic mental health condition such as schizophrenia; and
- helping carers is one way of helping those they care for.

5.63 In the past, mental health systems around the world tended to focus on the individual without considering the system in which they lived, often overlooking their roles within families and communities.[35] Yet the family usually has primary responsibility for care, with approximately 50% of those with severe mental illness living with family or friends, and many who do not, still receiving substantial support from them.[36] The cost of this care in Northern Ireland, if provided by the state, is estimated by the Sainsbury Centre for Mental Health to be £122 million.

5.64 The inter-relationships between service user, carer and other family members are important for each person's well-being. The carer who is a spouse may have to assume new roles and responsibilities. The carer who is a mother may concentrate on the ill family member to the neglect of others. A child whose parent is unwell may become a 'young carer' and may suffer adverse consequences.

5.65 Mental disorder can be demanding and stressful for a family. It can be intermittent, adding uncertainty to family life and an inability to plan in the short and long term. Children may experience difficulties at home but not speak about them at school because of stigma. Carers and families commonly experience fear of the unknown arising from lack of knowledge of the illness and its consequences, and grieving for the loss of future potential in their own lives and that of their family member.

5.66 Individuals within a family whose lives are affected by these circumstances must be identified and offered support in their own right in order to avoid adverse consequences to their health and well-being.

Carers

5.67 **Current Policy and Legislation.** Service providers have traditionally shown a reluctance to comprehensively address the needs of carers. However, the needs of those caring for others with severe and enduring mental illness are especially high and cannot be ignored. Valuing Carers[37] (2002), Northern Ireland's carers' strategy, recognises that carers' health needs must be met, that they must be provided with adequate information and be involved in the planning and provision of services.

5.68 Its key elements relating to carers of those with serious mental illness are:

Recognition

- all organisations must begin to recognise carers and be prepared and able to direct them to sources of support;
- older carers should be sought out and supported; and
- young carers should be identified and supported in their education and development.

Assessment

- carers should be informed of their right to a separate assessment, separately recorded.
- Information and Support
- clinicians should seek their patient's consent to provide relevant information to the carer;
- carers should be fully involved in the timing of hospital discharge and given the information they require for the aftercare of the patient. The carer's name should be included in the discharge letter to the GP;
- the training needs of carers must be assessed and training provided;
- handbooks of local services are required, as is information on the Internet; and
- locality-based and disability-specific self-help groups should be encouraged.

Services for Carers

- carer services should be reviewed with carers;
- reviews must be made of respite opportunities. Carers and service users must be involved in the reviews;
- a carer liaison or co-ordinator position should be created in each Health and Social Services Trust;
- carer advocates should be developed and trained; and
- front line staff should deal sympathetically with complaints.

5.69 The recent Carers and Direct Payments Order (Northern Ireland) 2003 entitles those who provide regular and substantial care to an assessment of their own needs and enables Trusts to provide services directly to carers after assessment. Assessments should be undertaken annually and a written care plan produced and implemented in consultation with the carer. In looking at the circumstances of both service user and carer consideration must be given to the degree of support a carer can, or is willing to provide, so that there are no adverse effects on her/his own health and well-being.

5.70 **Identifying the Carer.** Mental health professionals should know who is providing care and support. General Practitioners, other clinicians and mental health professionals should actively seek the consent of service users to provide their key carer with relevant information. This should be done on the basis of clear protocols for the identification of key carers.

5.71 Service users should be encouraged to nominate a key carer, who may not be a family member. This information should be reviewed regularly, as many carers would not identify with the term 'carer' or describe themselves as such, seeing their role simply as a family responsibility. The Review recommends the concept of a User-Key Carer partnership

5.72 **Partnership with the Carer.** Agencies and care providers should recognise and value carers and accord them equal status with other providers of care.[37] Working with service users and carers in partnership is conducive to the creation of holistic support networks, which are important in bringing relief from isolation and loneliness. A culture of creating and encouraging support systems for the whole family should be developed.

5.73 With the consent of the service user the key-carer should be involved in the drawing up of care plans, consulted about hospital discharge and periods of leave from hospital. Hospital admission and discharge are particularly difficult as they are often unplanned, with little or no involvement of patient or carer.[38]

5.74 **Information for the Carer.** Carers and families need a wide range of information to manage their day-to-day circumstances and alleviate the helplessness many experience. This would include information on social security benefits, the law, their own rights and entitlements and those of the service user. Social security benefits can create urgent problems around the times of hospital admission and discharge. Carers are generally not familiar with mental health legislation and the associated processes and structures. Carers need information about the structure of health and social services so that they can effectively deal with them.

5.75 On occasion the needs of carers and families for information may conflict with the wishes of the service user. While the fundamental right to confidentiality for the service user must be respected, a way forward should be negotiated to ensure that the needs of the carer and family are also met. A person-centred approach to the delivery of care will both highlight and moderate these conflicting rights, with measures which can be put into effect at times when the service user may not well enough to make informed decisions, such as advance directives, identifying and working in partnership with the carer, providing carers and families with information about the illness.

5.76 With the consent of the service user key-carers should be provided with information about the mental disorder affecting their loved-ones, including medication and its side-effects, what choices are available regarding therapeutic interventions, prognosis, how to get help, what to do in a crisis, how to deal with certain situations and symptoms.[39] Carers must be provided with names and telephone numbers of who to contact in a crisis. Carers need to be listened to when they report that a crisis is pending.

5.77 **Support for the Carer**. Stigma, guilt and shame can bring about a breakdown in natural, supportive social networks causing carers and families to experience a deep sense of isolation. Self-help groups provide an effective counteracting measure where people can speak about their circumstances, receive and give support and make sense of their experiences. A variety of flexible and responsive support mechanisms should be on offer to assist families in dealing with the many issues they face including helplines available during and after business hours, dedicated carer and family workers and opportunities for respite breaks. Carers of people with mental health problems find family worker support of value. It should be sensitive to ethnic diversity. A range of opportunities for breaks is required for users and carers. Partnerships involving the independent sector are often an effective way of providing this service. Support services for carers provided by the independent sector, and involving carers have particular advantages.[36]
Good Practice Examples (Annex 5.5.9)

5.78 **Empowerment of the Carer through Training**. Training programmes have been established to empower carers to respond to the challenges arising from mental health problems, increase their knowledge, develop coping skills and deal with grief and isolation. These should be made widely available. The anticipated developments in Home Treatment and Crisis Resolution make it imperative that carers receive appropriate training to carry out the tasks required of them.

They need to know about risk management and be advised about vulnerable periods such as the period following hospital discharge.
Good Practice Examples (Annex 5.5.10)

5.79 Family interventions can have considerable benefits for relatives' psychological distress, family functioning and the carer's relationship with the service user.[40,41] Despite its effectiveness, few carers and families currently have access to this form of support.
Good Practice Example (Annex 5.5.11)

Children and Young People

5.80 It is estimated that 30% of adults with mental health needs have dependent children. Rates of psychiatric diagnosis in these children range from 30% to 50% compared to 20% in the general population.[42] The presence of alcohol or drug misuse among parents can add significantly to the mental health difficulties of children. Service users may also be reluctant to seek help because of fear that children may be taken into care.

5.81 In the UK, it has been shown that children who become involved in the child protection system often have significant experience of parental mental illness, parental substance misuse and/or domestic violence.[47] A survey conducted in 2000 in the Northern Health and Social Services Board area found that 72% of the 467 children placed on the child protection register had a history of parental mental illness or substance misuse while, 79% of the 703 children who received services under the Children (N.I.) Order 1995 had a history of parental mental illness or substance misuse.[44]

5.81 The potential effects of mental health problems of parents and siblings on the health and well-being of children in the same household has been recognised for some time. These children are more likely to experience financial hardship, marital discord and social isolation than children in a household without a parent with mental health problems.[45] They may experience anxiety, extended periods of separation, disruption in schooling and, in a relatively small number of cases, neglect and/or abuse.[46] Other risks include:

- between 25% and 50% of children of parents affected by severe mental illness will experience psychological disturbance during childhood or adolescence with up to 14% of such children developing a psychotic disorder in adult life;
- risk may double for children where both principal caregivers are affected;

- risks to children increase during the acute phase of an illness and are exacerbated by marital breakdown, social isolation and stigma; and
- some children may become involved in parental symptomatology.[47]

5.83 The mode of delivery of services can sometimes reveal tensions in a system that has been primarily created to help adults, sometimes at the expense of their children. For example:

- patient confidentiality can sometimes be an obstacle to the sharing of crucial information;
- understanding of roles and responsibilities in multi-disciplinary teams can be highly variable; and
- inpatient facilities are often not best suited to the needs of parents, babies, small children and/or adolescents.

5.84 Routine good practice among child protection workers is to consider the special needs of children in these circumstances. However, there is no certainty that these needs are routinely taken into account during the course of assessments carried out by mental health workers. Although there is a wider recognition of child protection issues among all professions, the recognition of these issues by hospital based multidisciplinary teams varies. It is essential that the assessment process for parents with a diagnosis of severe mental illness includes an assessment of the needs of children within the household. Written child protection protocols and policies, agreed between child care and mental health services, are an essential element of good practice and it will be vital to ensure that such protocols remain in place and are reviewed as organisational structures change and evolve.

5.85 Support for the family must become an integral component of a comprehensive service which encourages a 'family wrap-around' approach.[43] Appropriate support must be provided for the children of those with mental illness so that they benefit from the same life chances as other children.[36] Their needs must be identified in the course of drawing up a care plan for the service user and they should be fully included and addressed in any subsequent care planning process.

5.86 Very young children may put additional pressure on the coping capacity of both service users and carers requiring measures to be taken to prevent extra stress within the home. These issues should be recognised as early as possible in the assessment process. In the longer term, children will need advice and help to 'navigate' their way through their education and transition to adulthood.

5.87 Children and parents value a range of supportive measures including:

- a contingency plan drawn up for times of crisis;
- maximum continuity and minimum disruption for children when their parent is admitted to hospital;
- an age-appropriate explanation for children of events surrounding an admission;
- the availability of a confidante for children during a crisis;
- facilitated access to other children in similar circumstances;
- continuity of family support workers;
- suitable visiting arrangements in hospital; and
- parental support groups.[48]

5.88 An agreed, formal protocol between children's and mental health services should be established for those responsible for delivering health and social care to families where children may require protection. This would govern the sharing of information, the management of cases and the identification of lead agency and key worker status and roles.

5.89 **Young Carers.** Some children may be undertaking levels of care that are considered inappropriate for their age. As a result 'Young Carers' have been highlighted as a priority group by government policy in recent years. These children and young people assume levels of responsibility for caring which impacts on their health, education and development.

5.90 Valuing Carers[37] makes specific reference to young carers and recommends that they are identified and that services are put in place to ensure that their development and education do not suffer as a result of their caring duties. The Internet should be considered as a means of making information available to them.

5.91 The key messages in guidance from the Department of Health, Social Services and Public Safety are that joint assessment of parent and children is necessary and that services should be comprehensive, flexible and timely.[34] Assessments can be seen as a means of supporting the family and of considering both their strengths and the areas in which they need support. Service users should be supported in their parenting and caring roles.

Good Practice Examples (Annex 5.5.12)

Resources

5.92 While much of the support that carers need to continue in their caring role is relatively inexpensive, additional resources are necessary. In England and Wales, the Government made available £140 million over two years, to facilitate the creation of a wider range of services to allow carers to take a break from their caring responsibilities. In resourcing changes to the mental health services in Northern Ireland, funding must be similarly earmarked and ring-fenced for carer and family support. The voluntary sector should continue to play a significant role in the provision of this support.

Recommendations

87. Boards and service providers must fully implement existing policy and legislative obligations relating to carers.

88. The needs of carers, children and other relevant family members, should be identified at assessment.

89. Key carers should be provided with appropriate support, education and information to carry out their role, as partners with the service user.

90. Agencies should accord carers equal status with other providers of care.

91. Key carers should be offered an annual assessment and a written care plan.

92. Family interventions should become an integral part of mental health practice.

93. Training programmes for dealing with mental health problems should be made available to all carers.

94. Service providers should ensure that a range of support services, in the form of helplines, self-help groups, directories of services, help with social security benefits and respite opportunities, is provided for carers and families. Providers should make available dedicated carer and family workers. The services of appropriately trained professionals should be made available for key carers.

95. Service users who are parents should be supported in their parenting role.

96. Children of people with mental health problems should be provided with appropriate support in their day-to-day lives and measures taken to support them in times of crisis, including the availability of a confidante.

97. Hospitals must ensure there are suitable visiting arrangements for families.

98. Agreed protocols must be established between child and adolescent services and mental health services where children may require protection.

99. Staff training must include engagement with carers and the assessment and management of their needs as carers.

CHAPTER 6

SERVICES FOR PEOPLE WITH SPECIAL NEEDS

6.1 Most people with mental health problems receive services exclusively at the primary care level. For people with more complex and more enduring mental health needs mental health services are required. There are, however, a number of specific mental health problems which cannot be fully addressed at either the primary or secondary care levels, usually because interventions are necessary which require specialist skills and specialist services. In this section of the Strategic Framework, the needs of people requiring such specialist services are addressed. We have identified eight specific areas:

- People with eating disorders;
- People with acquired brain injury or progressive brain disease;
- Deaf people with mental health needs;
- People with mental health needs arising from psychological trauma;
- People with personality disorders;
- People with Asperger's Syndrome or High Functioning Autism;
- People with disorders of gender and sexuality; and
- Women with perinatal mental health problems

6.2 While forensic services and services for people with substance misuse or alcohol related health problems are also specialist services, these are already established services and are therefore the subject of specific independent reviews, to be reported on separately. The interface between community and primary care and secondary care services with these services is dealt with in Chapters 3, 4 and 5.

6.3 Some of the services being considered, for example eating disorder services, are currently the subject of DHSSPS initiatives. In others, for example services for people with acquired brain injury or progressive brain disease, aspects of service development are already in progress. Nevertheless, the needs of people with more severe and often protracted mental health problems still require to be addressed.

6.4 A common aspect to the service requirements of people with special needs is a tiered approach to provision. That is, there are needs that can be met at a local level, whether community or primary care (Tier 1). Other needs can be met within local community mental health services (Tier 2). However for some individuals, some or all of their needs can only be met through highly specialised services (Tier 3 and 4).

SERVICES FOR PEOPLE WITH EATING DISORDERS (for background see Annex 6.1)

6.5 Services for people with eating disorders must be able to respond to the multidimensional nature of the problems presented, the different levels of severity and complexity and be able to cater for the needs of service users across the age range. There are now several evidence-based guidelines that give guidance regarding specific treatments.[1, 2, 3]

6.6 There is a relative lack of research-supported interventions in anorexia nervosa. The management of medical complications and nutritional rehabilitation is a priority. Structured psychological therapy by a competent therapist over a steady period of time is a central part of treatment. Family therapy is particularly helpful with younger sufferers. Medication may be required for co-existing psychiatric conditions but needs to be used with particular caution. Chronic, severe anorexia nervosa where the service user may not be fully engaged in treatment poses many challenges.

6.7 There is more research evidence for treatment interventions in bulimia nervosa. As before, physical stabilisation may be the immediate concern, particularly in view of potential electrolyte disturbance. A specific form of cognitive behavioural therapy (CBT) appears to be the clear treatment choice and this can be delivered in a variety of ways. Thereis some evidence that interpersonal therapy (IPT) can be as effective as CBT, but may take longer to work. Antidepressant drugs, in particular higher-dose fluoxetine, can rapidly reduce the frequency of binge-eating and vomiting but the longer-term effects are unknown.

6.8 The current guidance on atypical eating disorders is that they should be treated according to which of the above conditions they most closely resemble. The treatment of binge-eating disorder seems to be developing along the lines of treatments for bulimia nervosa with CBT based approaches and specific antidepressants being used to some effect.

6.9 Following extensive stakeholder consultation, consideration of good practice examples elsewhere and much strategic discussion, the DHSSPS has developed a Four -Tier Model of Service Provision that will aim to provide a comprehensive service for sufferers of eating disorders within Northern Ireland.

6.10 Tier 1 involves primary care services, voluntary organisations, self-help groups and families/carers. The development need in this area is in regard to health promotion, early detection, basic psychosocial intervention and effective physical monitoring. Tier 1 will require access to a comprehensive range of services at Tier 2-4.

6.11 Tier 2 involves assessment and intervention by existing community adult and child and adolescent mental health services and general hospital services, where necessary. These services offer more in-depth mental and physical health assessments and include short-term psychological treatments and longer-term support. This Tier will be important in the management of co-existing physical and psychiatric conditions.

6.12 Tier 3 is envisaged as the main provider of locally based specialist services within each HPSS Board area. Each Board has been tasked to establish a multidisciplinary specialist Tier 3 team in its area to provide an effective local response for people suffering from an eating disorder across the age range. In addition, teams will also provide training and supervision of practitioners within Tiers 1 and 2, shared care arrangements with primary care services, generic mental health services, obesity clinics and general hospital services as well as overseeing research, monitoring and evaluation of eating disorders services.

6.13 It is expected that the Tier 3 teams will come together as a regional network in order to share expertise and resources. These are likely to include the assessment and treatment of more complex cases, ‘gatekeeping’ for extra-contractual referrals and ongoing clinical supervision, training and professional development.

6.14 Tier 4 refers to specialist day patient and inpatient provision. Given the limited level of resources available and, in addition, that most people with an eating disorder can be successfully managed as an outpatient, the initial priority is to develop Tiers 1-3. However, once the regional network is established, it would be appropriate to examine both interim arrangements for inpatient provision elsewhere and to formally examine the need for inpatient beds within Northern Ireland over the longer term.

6.15 The Regional Eating Disorders Working Group is sensitive to the issues and difficulties that may arise in the formation of new specialist services, such as ensuring equitable provision and the recruitment, training and retention of adequate numbers of staff. The principles of good communication, interagency coordination and collaborative planning are viewed as being essential to the service development process.

Recommendations

100. The Regional Eating Disorders Working Group needs to continue its work of overseeing the strategic planning and practical implementation of eating disorders service development.

101 DHSSPS and service providers should establish Tier 3 teams.

- Tier 3 teams should define local operational policies and form a regional network enabling expertise and resources to be shared across the Province.
- Tier 3 teams should support Tiers 1 and 2 through training, supervision and shared care arrangements.

102. Strategic planning should continue for longer term needs such as Tier 4 services and the further development of specialist child and adolescent mental health services.

SERVICES FOR PEOPLE WITH ACQUIRED BRAIN INJURY OR PROGRESSIVE BRAIN DISEASE

(for background see Annex 6.2)

6.16 A four tier model as described by the Health Advisory Service[4] should be adopted to plan comprehensive service provision to meet the mental health needs of people with acquired brain injury (e.g., arising from trauma, haemorrhage, anoxia, infections, toxins including alcohol, nutritional deficiency, epilepsy) and progressive brain disease (e.g. Multiple Sclerosis, Parkinson's Disease, Huntington's Disease, early onset dementia).

6.17 **Tier 1: Primary Care Services**

Primary care services working with non-statutory organisations, families and carers are essential in addressing mental health needs, through medical treatments, education and psychosocial interventions. They should be supported through a range of services at Tier 2-4 levels.

6.18 **Tier 2: Secondary Care Services**

Mental health services play an important role in addressing the needs of people with acquired brain injury or progressive brain disease. Linkages between adolescent, adult and older adult mental health services are important to ensure smooth transitions across these services. Close collaborative working relationships between mental health and physical disability services are essential. Specialist expertise needs to be integrated within both mental health and physical health and disability services to ensure that they have the capacity to address needs.

6.19 **Tier 3: Dedicated Community Based Services**

Services dedicated to the needs of those with acquired brain injury or progressive brain disease are required at local provider levels. Such services should include the expertise to address mental health needs. Community Brain Injury Teams already provide services promoting recovery and community reintegration for those with acquired brain injury and have demonstrated their effectiveness within this area[5]. They work directly with the service users and their families and in collaboration with local statutory and independent services. Dedicated multidisciplinary services for adults with progressive brain disease should be developed to optimise service user functioning across the physical, cognitive, emotional and social aspects of their lives.

6.20 Specialist residential and supported living facilities are required to address the needs of those with acquired brain injury or progressive brain disease, who also have emotional, social behavioural or other mental health problems. *Good Practice Examples (see Annex 5.6. 1-3).* A range of individual facilities are required to meet the differing needs of those with acquired brain injury or progressive brain disease. Flexibility regarding access is required, with a focus on individual needs rather than on diagnostic category.

6.21 **Tier 4: Regional/Sub-regional Specialist Services**

Specialist services to promote mental health and well-being and neurobehavioural recovery are required. A specialist multidisciplinary mental health team with core inputs from neuropsychiatry and clinical neuropsychology/clinical psychology is required. This team would offer expertise in the assessment, diagnosis, therapeutic interventions and management of mental health needs of people with acquired brain injury and those with progressive brain disease. It should provide direct care to people with complex mental health problems, together with a consultation/liaison role to a range of medical specialities (e.g. neurology, rehabilitation medicine, general medicine, geriatrics, psychiatry and older adult psychiatry). It should also provide a consultation role to dedicated community services for people with acquired brain injury or progressive brain disease (Tier 3) and sessional input to the Regional Brain Injury Rehabilitation Unit.

6.22 A specialist inpatient facility is required for people whose behavioural difficulties are so severe that they cannot be managed within other services. This facility would offer multidisciplinary mental health assessment and treatment, aimed at reducing the behavioural problems that impede community placement. Teams generally comprise clinical neuropsychology, neuropsychiatry, specialist occupational therapy, physiotherapy, speech and language therapy, social work and RMN trained nursing staff.
Good Practice Examples (see Annex 5.6.4).

Recommendations

103. Planning and Development. Services should be developed to address the psychological and mental health needs of people with acquired brain injury or progressive brain disease, their carers and families. Partnerships are required across statutory and independent sectors. Service planning must involve clinical leaders, users and carers. Local information on needs must inform planning and development of services:

– Local primary care and secondary care physical disability and mental health services should be strengthened.

– Priority should be given to the ongoing development of community brain injury teams throughout Northern Ireland.

– Service planning for those with progressive brain disease must address the cognitive, emotional, social, behavioural and mental health needs of this group. An emphasis should be placed on multidisciplinary team working within community based services for people with progressive brain disease.

– Development of day care, respite, residential and supported living options are required for those who present with cognitive, emotional, social, behavioural and other mental health problems associated with acquired brain injury and progressive brain disease.

- A specialist regional mental health team is required to offer expertise in the assessment, diagnosis, treatment and management of mental health problems in acquired brain injury and progressive brain disease.
- Maine Neurobehavioural Unit should be enabled to develop fully as a regional specialist service. This might provide services on an all-Ireland basis.
- The development of care pathways is required to develop links and networks between different services and service components for both brain injury and brain disease.

104. Partnerships. Partnership between statutory and independent sectors and within statutory sector organisations (health, housing, education, employment and training) should be pursued, to ensure a comprehensive range of service provision.

105. Workforce. A workforce strategy is required to ensure that there are sufficient numbers of appropriately qualified staff, across the range of disciplines, required to enable service developments to address the mental health needs of both acquired brain injury and progressive brain disease.

- Attention to skill mix and the development of new job roles in required.
- Attention to the training and ongoing development needs of specialist staff is required.
- Specialist services should provide training and support to local community services and to care staff working in acute hospital, residential and day care settings.

SERVICES FOR DEAF PEOPLE WITH MENTAL HEALTH NEEDS (for background see Annex 6.3)

Specialist Mental Health Services for Deaf People

6.23 With the introduction of the Disability Discrimination Act (1995) and the modernisation of mental health services, particularly the development in community based provision, there is an opportunity to address issues of equality of access, and the needs of minority and excluded groups. The Department of Health consultation document "Sign of the Times"[6] outlines proposals for future developments for deaf mental health services. There should be a tiered approach to the provision of mental health services for deaf people[7].

6.24 Outreach Clinics in Northern Ireland from the Birmingham and Solihull specialist service have provided assessment and treatment, and patients have been admitted to their beds. Teaching, liaison and joint working have established a basis for further local service development. The recent appointment of a part time specialist consultant psychiatrist in Northern Ireland and a full time community psychiatric nurse, and the planned appointments of other team members, create an opportunity to offer locally based clinics and community services. The planning of future services will include consultation and involvement of service users and carers.

6.25 **Primary Care Services.**

Patient access to primary care should be improved to comply with the implementation of the Disability Discrimination Act. Deaf awareness training, technology such as loops and text phones, and access to interpreters should facilitate assessment and referral by GPs. At present social workers for deaf people initiate many psychiatric referrals. These need to be channelled through GPs, as for hearing people, but with joint working, as required.
Good Practice Example (see Annex 5.6.5)

6.26 **Hospital Inpatient Facilities.**

Hospital inpatient facilities are required for a small number of clients with more acute mental health problems[8]. Consideration should be given to developing such a facility on an all-Ireland basis[9].

6.27 **Deafened and Partially Hearing People.**

Specialist deaf services should have a low threshold for assessments, including for deafened or partially hearing people, in any circumstance where a mental health problem is suspected, and the person's deafness is significant to him or her. Mental health input to rehabilitation programmes for deafened people is essential to address the additional stresses due to anxiety and depression which frequently occur.
Good Practice Examples (see Annex 5.6.6)

6.28 **Training.**

There is clearly a need for training of mental health workers in the psychological, sociological and psychiatric aspects of deafness[10] and the training of staff as mental health professionals.
Good Practice Examples (see Annex 5.6.7)

Recommendations

106. There should be a tiered approach to the provision of mental health services for deaf people. A regional plan for services should be developed with service user and carer involvement and should include audit, research, teaching and health promotion. There should be effective interfaces and liaison between primary care, social services, voluntary organisations and the deaf community. Protocols for effective joint working between local Community Mental Health Teams and services and the specialist mental health service for deaf people should be developed.

107. Long-term plans should be developed for the local establishment of inpatient facilities, possibly on an all-island basis.

108. The deaf service user must be given full information about his or her rights and referred as soon as possible to specialist services, if they are required.

109. For deaf people being assessed for inpatient admission, protocols must be developed for the use of interpreters and other relevant professionals, such as Social Workers with deaf people, in addition to the Approved Social Worker. During an admission period, appropriate and accessible communication support must be provided within a maximum of 24 hours. All service users should be enabled to give fully informed consent for their treatment, or to appeal against it.

110. Primary care teams should be provided with appropriate information about mental health & deafness services to enable them to refer service users for specialist assessment.

111. Deaf Awareness training, appropriate technology and access to communication support, especially interpreters, are essential for those working with the Deaf Community.

112. Staff in Community Mental Health Teams and services must be provided with knowledge and skills to enable them to work, if necessary through interpreters, with deaf people, including staff in day services and out-of-hours services.

113. Specialist mental health services for deaf people must:

- develop a multidisciplinary team which should include deaf professionals;
- provide assessment and treatment for service users at clinics in all the Health and Social Services Boards and in the community;
- work jointly with primary care, local mental health teams and other specialist mental health services, including with learning disability, older adult forensic and psychological therapy services;
- carry out preventative work including provision for deaf children, adolescents and their families, rehabilitation programmes for people with acquired deafness.

114. Specialist mental health services for deaf people should work with other agencies including education, social services, the independent sector, deaf community organisations, employment and housing.

SERVICES FOR PEOPLE WITH PSYCHOLOGICAL TRAUMA (for background see Annex 6.4)

6.29 **Policy and Philosophy.** Northern Ireland (CREST) guidance on the management of Post Traumatic Stress Disorder (PTSD) in adults was issued in 2003.[11] This followed the guidance issued by the International Society for Traumatic Stress Studies[12] (2000) and the Department of Health,[13] which, on the basis of available research evidence, pointed to the treatments of choice for (inter alia) PTSD. In 2004, The National Institute for Clinical Excellence (NICE – England & Wales) issued draft guidance on the treatment of PTSD in both adults and children (with a final version of this guidance expected in 2005). The CREST guidance is a key element in the development of an evidence-based approach to the understanding, recognition, treatment of PTSD and related conditions. It forms a key building block in the development of a response to this area of need and should form the basis for the development of policy, services and training.

6.30 Key to the recognition, assessment and treatment of people suffering from PTSD, and related conditions, is the level of awareness amongst professionals and organisations that represent first points of contact. Beyond detection of psychological trauma lies the important task of evidence-based assessments, which examine in detail the specific impact on each individual who is referred, including associated needs, risks and complicating factors.

6.31 The development to date of services has been piecemeal and patchy, and lacks both a managerial and professional coherence. The development of the CREST guidance represents a significant building block in addressing these shortcomings. The establishment of a managed service network, identifying the contributions of all providers of services would enable significant progress to be made. Service pathways and menus should include the contributions of clinicians who have been treating trauma, mainstream mental health services, voluntary and community organisations supporting those affected by trauma-related disorders, Trauma Advisory Panels and specialist trauma services.

6.32 Given the developing understanding of needs arising from exposure to traumatic experiences and the implications for functioning and health, the developing knowledge and skills base in recognition, assessment and treatment, and the emergence of clear guidance on treatment etc. there is a strategic opportunity for progress in this area.

6.33 **Identification, Referral and Treatment.** Whilst research demonstrates that those who have mental ill-health are at higher risk of developing post trauma-related conditions, other considerations are important in terms of identifying and providing treatment for trauma-related needs. Clinical experience demonstrates that many people who have had no significant mental health ill-health prior to the trauma have acquired a post trauma condition. Further, it is well established that avoidance of any reminders of the traumatic experience (including the prospect of seeking treatment) is a key component of trauma-related conditions. These features (and the additional sensitivities required by the context of the Troubles) point to the need for specific response to needs and potential needs. Particular groups of those affected by violence, whose ability to access services is adversely affected by the context of the Troubles and who have multiple psychological, mental health and social needs, would benefit from a multi-agency and multi-professional approach.

6.34 **Training.** Treatment services should employ appropriately trained staff, preferably drawn from a range of professional backgrounds to provide added value and perspective to the assessment and treatment of people with trauma. Further, staffing levels, experience and skill mix must be geared to the provision of effective care at each level in the service tiers. Clarity about what a service can (and cannot) offer should inform recruitment and training strategies. Appropriate training in evidence-based practice (appropriate to each level) is required for staff involved in identifying, assessing, treating and supporting people with trauma-related needs.

6.35 Viewed from a potential service user perspective, the response of the health and social care services (statutory and independent) should reflect the following characteristics:

- clear and non-bureaucratic points of access to information and services;
- proactive awareness of and sensitivity to potential trauma-related needs by key first-point-of-contact professionals and organisations;
- effective first line responses offering reassurance, clear information, initial care, and onward referral;
- active response and follow up to reduce the potential for drop-out associated with avoidance;
- individualised care to reflect the highly individualistic presentations of trauma-related needs, and the personal associated circumstances (e.g. other illnesses, financial hardships, disability etc.) and any co-morbid mental ill-health needs;
- access to a range of evidence-based therapeutic resources;
- services should place a clear emphasis on creating a safe and confidential treatment environment; and
- services should have in place key links and arrangements to respond to urgent and other needs that cannot be met within the specific service.

Recommendations

115. The development and expansion of evidence-based services, including CREST guidelines, to address psychological trauma and including adult survivors of childhood trauma should be taken forward as a priority. The expertise developed in the non-statutory sector should inform the development of the overall trauma network.

116. To facilitate progress, a coherent tiered strategy should be developed, based on a managed service network:

– service planning must involve clinical leaders, users and carers and clinical managers;

– an audit of what is currently available (i.e. resources and skills), tested against the CREST guidance (2003), should be undertaken;

- future service configurations should build upon the experience and expertise that has been developed in both the statutory and non-statutory sectors;
- standards should be developed to support the development of and access to services.

117. Primary care staff (and other front line services), in line with CREST guidance, should be provided with the necessary guidance, training and support in the detection, preliminary intervention and appropriate referral of people with trauma-related needs.

118. A workforce plan, which addresses staff levels and qualifications, training and re-training, should be developed.

- Training. Pre-professional training for health and social care professions should include appropriate content on the conceptualisation, recognition and treatment (including referral) of psychological trauma.
- Advanced training for the treatment of PTSD (and related conditions) should follow current evidence-based guidance on the management and treatment of psychological trauma.

119. Health promotion programmes to address the specific needs of those affected by traumatic events should be developed in line with evidence-based practices and principles.

120. Organisations which employ people who, in the course of their work, may be exposed from time to time to traumatic experiences should put in place measures relevant to the nature of the work and risks.

SERVICES FOR PEOPLE WITH PERSONALITY DISORDERS (for background see Annex 6.5)

6.36 In line with guidance in other parts of the UK, people with a personality disorder who experience significant distress or mental illness as part of their disorder and the mentally ill who suffer from co morbid personality disorders are part of the business of mental health services.[13] The needs of Personality Disordered Offenders within the criminal justice system are considered separately by the Forensic Services Expert Working Committee. Services for people with

Personality Disorders should be accessible and bring discrete components of care together including psychotherapy, medication, housing, social care.

The National Institute for Mental Health in England has proposed a generic service model.[14] The model is a 'hub and spoke' specialist service supported by local initiatives it is a tiered structure, as in the prototype being developed in the Thames Valley Personality Disorder Initiative.

6.37 **Tier 1.** At community and primary care early detection is important. Interventions include psychoeducation, guided self-help and basic psychological interventions. The voluntary agencies have an important role in providing information, support, advocacy and an avenue through which families and carers can contribute. User-experts should be supported in the provision of support and education, eg to housing officials, schools, those involved in social care provision.

6.38 **Tier 2.** Mental Health Services may be necessary if other significant mental disorders co-exist and when needs cannot be met at Tier 1. A number of service models have been developed ranging from the sole-practitioner model, through divided function model to liaison-consultation. Essentially, the service user is supported through a CMHT either by a dedicated practitioner, with the support of other team members or within the team, supported by an expert in this field. A fully integrated service would provide therapeutic interventions at all levels, with one point of entry for expert assessment, clear referral criteria and explicit indicators for treatment in different components of the service.

6.39 **Tiers 3 & 4.** A Specialist Team to provide Community/Outpatient/Day Hospital and Therapeutic Community Services. Clinical outcome and economic studies support this development. The main roles of this service include assessment and therapeutic interventions for people with more severe and complex needs. Interventions include structured specialised therapies, medication, social and housing management. Specialist services must also provide teaching, training and supervision for Tier 1 & 2 services, lead in audit and research, and oversee the function and development of the overall service.

Recommendations

121. Specialist services for people with personality disorder must be established to augment secondary care services. Service planning must involve clinical and service leaders, users and carers and the independent sector.

- Service requirements should be the subject of needs assessment.
- Residential and day treatment services for people with personality disorders should be established in Northern Ireland.
- Specialist multidisciplinary teams should be established to provide assessment, education and support to other services who may come into contact with people with personality disorders.

122. Specialist services for people with personality disorder should co-ordinate with other mental health services such as forensic services, substance misuse and with learning disability services.

123. Training. Specialist services must provide education and support for staff in the diagnosis and management of people with personality disorders. In primary and secondary care, awareness training of the needs of those with personality disorders should be provided for such services as primary care, A&E, perinatal services, medical and surgical staff.

124. User and Carer initiatives to support service users and carers of those with personality disorders should be facilitated.

SERVICES FOR PEOPLE WITH ASPERGER'S SYNDROME OR HIGH FUNCTIONING AUTISM (AS/HFA)

(for background see Annex 6.6)

6.40 The following requirements have been identified consistently in research audits for people with Asperger's Syndrome or High Functioning Autism (AS/HFA):

- training and awareness programme to increase professional understanding across a wide range of community services including social, housing, school, continued education, health and employment services;

- clear support pathway so families know who they can contact to request assessment regarding possible diagnosis;
- an improvement in employment opportunities, support and training;
- interventions to reduce social isolation and clinical mental health difficulties;
- interventions to develop independent living skills, relationships and personal development;
- better post-diagnostic emotional support, information and advice for people with AS/HFA and their families;
- a range of appropriate supported and independent housing options;
- better social and academic support and learning opportunities within secondary schools during transition and continued education;
- carers' needs to be assessed and met, including education/information, advice, counselling (including genetic counselling, if appropriate) and 'respite' type services, such as befriending for their sons and daughters;
- more appropriate service provision. Many adults are placed in services that are not suitable for AS/HFA, due to poor provision or misdiagnosis;
- access to advocacy services, for families and people with AS/HFA;
- sensitive crisis intervention (not necessarily mental health inpatient);
- forensic services (to support the minority of people who display behaviour likely to put themselves or others at risk of harm).

6.41 A tiered service including the service needs of people with AS/HFA is recommended. The initial priority is the formation of a core team (Tier 3) in each Board area, with the necessary expertise to provide training and support for local providers. Based on current evidence, such a team should include professional input from clinical psychology, occupational therapy, psychiatry, family support co-ordinators and intervention therapists to assess and support housing and employment. Services for people with AS/HFA must be identified at local provider level (Tiers 1 and 2) in response to local assessment of need and with the support of Tier 3 services. Adequate information systems must be developed to assess need and inform service planning.

6.42 **Assessment and Diagnosis.** In considering the needs of people with AS/HFA, the following points are highlighted:

- complex cases require highly specialist diagnostic assessment. Professional background is largely irrelevant, whereas expertise in autism and knowledge of current diagnostic classification systems is of paramount importance;

- co-morbidity of AS/HFA with mental illness, indicates strongly a need to have the combined knowledge of professionals experienced in each (few possess expertise in both mental illness and autism at the present time);
- co-working between programmes of care within Health & Social Services will be necessary for the foreseeable future, until mental health professionals acquire the requisite additional skills in diagnostic evaluation.

Therapeutic Interventions.

6.43 A range of interventions are required:

- Management of psychological problems will require consideration of the social environment ie support needed to access employment opportunities and housing options, interventions to reduce social isolation, develop independent living skills and relationships, and to foster personal development;
- Drug treatment may be indicated if there is a clearly identified co-morbid mental disorder, but is never an effective long-term solution for behavioural problems;[15]
- Autism and Autistic Spectrum Disorders (ASD) are accepted as being neuro-developmental in origin. The resultant impairments of people with AS/HFA mean that psychodynamic therapy and reflective counselling are not appropriate. Use of these approaches in the past has been reported to cause unnecessary confusion and distress for the individuals and their families.[16,17,18] Any therapy that attempts to 'treat' the core symptoms of AS/HFA as an emotional issue will be counter-productive, as will therapists and counsellors who do not understand the psychological theories of autism;[26]
- Cognitive Behavioural, Behavioural, and Personal Construct Therapy by a skilled practitioner who can adjust intervention to the deficits of ASD, are regarded now as the most beneficial; [19,20]
- Research on the inner experience of people with autism and AS/HFA also supports the use of visual strategies as appropriate and effective adaptations to such therapies for these individuals; [21,22]
- In addition, it is beneficial to help adults with AS/HFA understand the expectations and perceptions of others, to develop social skills, to understand personal needs and develop concrete strategies for meeting those needs, and to manage their anxiety.[22]

6.44 It is essential to provide support for the individual and their family in understanding the disability and adjusting to confirmation of a diagnosis – usually after many years of uncertainty and self-blame. Many cases have reached crisis point for both the referred person and those who are struggling in their efforts to live with, and help them.

6.45 Local research indicates high levels of psychological distress and mental ill-health amongst the parents of AS/HFA adolescents and adults. It revealed that 25% of carers have a diagnosed mental health problem, with an additional 28% reporting significant symptoms of stress and anxiety. These were attributed directly, by parents, to the difficulties associated in caring for their son or daughter.[23]

6.46 Research carried out by the NAS[17] reported that 70% of carers felt that finding appropriate care facilities was the major barrier to them accessing work. This research also highlighted the responsibility of social services to urgently prioritise support for carers. Bernard et al[24] noted that parents are often the sole carers for their son or daughter with ASD, providing regular and substantial amounts of care.

6.47 It must be noted too that adults who are in long-term relationships are being identified increasingly. In such cases, their spouse or partner requires equal support to parents of those with AS/HFSA. Carers of individuals with ASD can be supported in their caring roles. Yet, when this does not happen, costs to the individual and their family are considerable.

6.48 Some people with AS/HFA will not require any statutory services. However, most diagnosed adults need understanding and support from specialist services, but currently cannot access existing health and social care because they do not ‘fit’ the perceived remit of mental health or learning disability services.

6.49 Without appropriate provision many adults with AS/HFA will become socially isolated, drop out of school or college, will be unable to work, will suffer mental health problems and psychological breakdown. The suicide risk for people with this condition must also be recognised.

6.50 Lack of support services for people who are experiencing difficulties can lead to police involvement, prison sentences, admission to psychiatric units and trial-and-error drug treatments.[25] These consequences could be avoided for many, or reduced greatly, by a relatively low level of ongoing support, saving severe distress and the costs of inappropriate agencies becoming involved.

6.51 The range of needs experienced by adults with AS/HFA demands a person-centred approach from agencies to provide them with the required services and support. Many will need significant and ongoing assistance to achieve maximum independence. 'There is need in some cases for specialist services, but there is a wide need for existing services to develop specialist approaches'.[26]

6.52 Housing. Only 54% of adults with ASD reported that they were satisfied with their living arrangements and only 3% with AS/HFA live fully independently.[25] More adults with a disability live in the family home than in any other setting. Many individuals with AS/HFA are vulnerable to abuse and exploitation and have a range of housing needs, from independent living to supported housing. Even independent living often requires an element of support to help people with ASD cope with day-to-day demands and unexpected situations.

6.53 Appropriate 'respite' care provision is required, from befriending to short-term breaks that would allow adults with AS/HFA, and their families, the necessary time apart to prevent the crises that can lead to ultimate breakdown.

6.54 **Employment.** National Autistic Society research[27] reported that many more people with ASD could and would be able to work if better support were available. Despite having a strong desire for employment, only 12% of adults with AS/HFA are in a paid position. A UK economic study in 2000 estimated the average additional lifetime cost of a person with AS/HFA at almost £800,00.[28] With appropriate intervention, adults with AS/HFA can be supported in employment and achieve their full potential as citizens.[29]

Recommendations

125. A needs assessment of people with AS/HFA and their families should be completed as a priority

126. The mental health programme of care should assume overall responsibility for ensuring the development of services across health and social services for all people with ASD including Asperger's Syndrome/High Functioning Autism. Service planning must involve users and carers, clinicians, relevant statutory and voluntary organisations.

127. Assessment. Multidisciplinary teams should be established for each provider area for specialist assessment services (Tier 3) with clear pathways to service access.

128. Appropriate, timely person-centered interventions should be provided based on best available evidence
- clear referral pathways to mainstream services (Tiers 1 and 2);
- specialist interventions by appropriately trained specialists (Tier 3)

129. Individual and family support. Emotional and practical support and resources must follow assessment in a timely fashion and is especially required at times of transition (eg leaving school). Appropriate respite services must be developed. Access to leisure and meaningful activity should be assured. Social inclusion including opportunities for further and higher education and employment should be supported. A range of supported accommodation should be developed.

130. Training. Provider units should ensure the provision of training for parents and staff. Staff training specific for the service needs for people with ASD should be assured within the workforce training strategy at regional and provider levels (Recommendations 23 & 62), including awareness training and specialist training.

131. A senior manager in each provider unit should have overall responsibility for the development and delivery of services for people with ASD.

SERVICES FOR PEOPLE WITH DISORDERS OF GENDER AND SEXUALITY

(for background see Annex 6.7).

6.55 In the past year, a strategy group has been established by the DHSSPS, with representatives from the four Board areas to examine the provision of psychosexual services and, in particular, those for transpeople. There is a general view that, as individuals with sexual dysfunctions often have comparatively less complex problems and usually require shorter periods of intervention often with simpler interventions, their needs usually should be addressed locally. This would mean that individuals with more complex cases (in particular disorders of gender and sexual preference) would be referred to the more specialist services in Belfast (and where appropriate Omagh). This would also facilitate more of a focus in the Belfast service on the needs of transpeople and individuals with disorders of sexual preference.

6.56 From a recent survey on services available for transpeople in Great Britain[30] services were often so distant from patients' homes that there was real difficulty in supervising key areas of the patients' assessment and treatment due to unfamiliarity of service staff with the local circumstances of patients.
Good Practice Example (see Annex 5.6.8)

6.57 With the introduction into the psychosexual service in the Belfast City Hospital of psychoanalytically based treatments, there is now an opportunity in Northern Ireland for the management and treatment of patients with disorders of sexual preference who would previously have been referred to very specialist centres such as the Portman Clinic in London. This element of treatment could also provide a beneficial service to patients in the new Regional Secure Unit, as there is an acknowledged higher level of disorder of sexual preference in this group and an acknowledged link between violence and perverse behaviour. However, development of this element of service (as with gender services) will depend on whether more locally based services for sexual dysfunction can be progressed.

6.58 The planning and strategic process will need to address:

- the means of establishing a more locally available treatment for sexual dysfunction and the relationship of this to central specialist services;
- the refocus of specialist services on the more complex conditions;
- a specific focus on Gender Identity Disorders, giving consideration to replicating in Northern Ireland the Scottish Needs Assessment (SNAP) Survey (2001), in order to identify fully the needs of transpeople and also inform a more co-ordinated system of services.

Recommendations

132. People with disorders of gender and sexuality in Northern Ireland should be offered the full range of services which have been shown to produce positive therapeutic outcomes. Service planning must involve clinical leaders, users and carers and clinical managers.
   - As contact with services is often long-term, the majority of provision should be local and community based, with appropriate access to regional specialist services when this is required.
   - Services should be community based and person-centred.
   - Regional services should be targeted at individuals with the most complex needs.

133. There is a need to evaluate the workforce requirements for service changes and for training.

SERVICES FOR WOMEN WITH PERINATAL HEALTH PROBLEMS

6.59 For women, childbirth is the time of greatest vulnerability for becoming severely mentally ill. About 10% of all recently delivered women have a major depressive illness. The incidence of admission to hospital for puerperal psychosis is 2 per 1000 women delivered and about 2 per 1000 women delivered in the UK are admitted to hospital suffering from non-psychotic conditions.[31,32]

6.60 The antenatal period and the contact it brings with obstetricians and other antenatal staff offers a unique opportunity to identify and screen women at risk. The risk of relapse or recurrence of psychotic mental disorder is well established and factors that increase the risk of non-psychotic postpartum mental disorder can also be identified. Close liaison between mental health professionals and members of the obstetric team is essential for addressing mental health needs of women during pregnancy and the puerperium.

6.61 Perinatal mental health problems need to be addressed with a clear regional strategy focused on the different levels of services required and ensuring that all staff involved receive adequate training and support.

6.62 Puerperal mood disorders occur across a spectrum of severity ranging from mild depressive disorders through to puerperal psychosis. The conditions in general are very responsive to treatment and, if treated early and effectively, have reasonably good prognoses. At one end of the spectrum all that may be required is simple reassurance, whereas at the other, hospital admission and specialist treatment are needed to prevent adverse outcomes. The vast majority of puerperal mood disorders can be dealt with and managed at primary care level. Staff require training and support from secondary services.

6.63 An essential part of the tiered service provision for women with perinatal mental health needs is a specialist perinatal mental health service. This service has a number of functions including assessing and managing those suffering from puerperal psychosis and other severe postnatal mental disorders. It would provide a range of facilities including community based alternatives to hospital.

6.64 In addition, specialist services can advise on and, where necessary, provide services for people with continuing mental health problems who become pregnant whilst under the care of adult mental health services. It would provide an obstetric liaison service, assessing mental health problems associated with pregnancy or the postpartum period and respond to emergencies. It would liaise with primary healthcare professionals to assist in the management of less serious mental health problems. It would provide prenatal counselling and high risk management for women at risk of developing postpartum mental disorder. It may undertake the assessment of women with complex and enduring mental health problems. It would also take a lead role in the development of services at all levels of healthcare provision, contribute to the education and training of other healthcare professionals and engage in research and innovative practice.

Recommendations

134. A regional specialist mental health service should be established for women with mental health problems occurring in the perinatal period. The requirement for inpatient mother and baby facilities should be the subject of a regional needs assessment.

135. Protocols for the management of women who are at risk of a relapse or recurrence of a serious mental disorder during the perinatal period must be in place in every provider unit with maternity services:

    – comprehensive assessment of maternal health must include mental health.

136. Women who have a past history of serious non-postpartum mental disorder, should be offered assessment by a psychiatrist in the antenatal period and a management plan instituted regarding the high risk of recurrence following delivery:

    – substance misuse services should be accessible throughout antenatal care.

CHAPTER 7

SUPPORTING CHANGE

INTRODUCTION

7.1 The Framework outlined in Chapters 3 to 6 provides a road map for major reform of mental health services for adults. It will take 10-15 years to achieve and depends on a number of underpinning elements and processes. Four key elements are considered in this section of the Review:

- Workforce requirements, including its magnitude and the necessary skills;
- Financial resource based on a sound economic appraisal;
- Information to support management of services, the Review process and to monitor change;
- Research and development.

DEVELOPING THE WORKFORCE

Introduction

7.2 The vision and principles underpinning the Strategic Framework recognise the fundamental importance of the workforce in delivering the aims and goals of the Strategic Framework. The Strategic Framework is premised on a significant increase in the workforce. The capacity to deliver the vision turns on having an adequate workforce, appropriately trained and working effectively together and in partnership with service users and their carers to achieve meaningful change in the quality and standards of care delivery throughout Northern Ireland. The demands of the workforce to see through the changes and to deliver the Strategic Framework require attention to workforce health needs including the need for support and supervision.

7.3 Northern Ireland is fortunate in having a motivated, stable and skilled workforce in most of the disciplines involved in mental health care. Our educational establishments provide quality training and education at further education, undergraduate and postgraduate levels in a wide range of the areas necessary for skilling the workforce.

7.4 Nevertheless, there are a number of challenges in the workforce situation that will need to be addressed as a matter of priority if the Strategic Framework is to achieve its objectives. These challenges include:

- difficulties in recruiting suitably qualified staff;

- the need to recruit unqualified staff and train them;
- pressures on staff to leave for better pay and conditions offered elsewhere;
- the need to develop effective strategies to retain existing staff; and
- reduction in the number of people available to volunteer.

Current Work

7.5 The anticipated need for substantial development in the workforce triggered a joint planning initiative between the Review and the Department. The work of this Group forms an essential pre-requisite to an effective workforce strategy for Adult Mental Health and includes analysis of the current workforce, mapping the skills and competencies, defining the changes required in educational arrangements to address both the demand profiles of the workforce and their skills requirements, including the training needs of non-qualified staff. The emerging findings include evidence of shortage of staff in all areas, problems in relation to career progression, considerable variability in training opportunities, the need for incentives for the retention of staff.

Proposals

7.6 The Review recommends the establishment of a Workforce Strategy for mental health adopting the recommendations emerging from the Workforce Planning Group including:

- the establishment of a Workforce Development Group;
- the establishment of a central Information and Advisory service about careers;
- collaboration with training providers and regulatory bodies to develop “Fit for Purpose” training;
- agreeing with service providers targets for recruitment and retention across Northern Ireland, across the statutory and voluntary sector; and including the participation of service users;
- addressing skill mix issues, for example the training of nurses to prescribe, using more support workers to complement the role of trained staff;
- ensuring that appraisal systems based on agreed National Occupational Standards are in place to identify staff development and training requirements;
- joint working between the health and social care sector and training sector to ensure appropriate training opportunities to required standards are available accessible;

- the development of a qualifications framework which includes a range of qualifications and an assessment strategy to encourage career progression and flexibility between professional groups; and
- joint working between DHSSPS and service providers on the improvement of organisational culture, including stress reduction and management programmes, increased flexible working and improved work/life balance.

INFORMATION

The Role of Information in Mental Health Care

7.7 Good information is at the heart of high quality mental health care and decision making. It comes in many forms:

- individual data held in personal records (eg a patient file);
- consumer and professional surveys (eg a satisfaction survey of carers);
- service performance reviews from inspection and inquiry reports (eg Mental Health Commission reports);
- governance and risk management reports (eg an estates report on environmental problems within an acute ward);
- needs assessments (eg a research study of the prevalence of psychiatric illness within a city);
- financial information (eg a monthly budget report to managers);
- aggregated activity data (eg how many admissions occurred within a specified period of time);
- service directories (eg a directory of counselling services); and
- human resource records and reports (a strategic workforce planning report).

7.8 Without these sources, clinicians, practitioners, managers, planners and commissioners would be unable to deliver the sort of care and service expected by the general public. With the advances in information technology and a growing expectation that better information will lead to better services, there is an increasing drive in modern mental health services for:

- fully integrated service user records;
- routine, anonymised data analysis at population level;
- widely accessible consumer information on problems and services;
- speedy dissemination of the evidence base; and
- continuous service improvement through improving information analysis.

7.9 Information gathering will become increasingly important for the evaluation of outcomes, performance management and for population needs, based on aggregated individual assessments. These objectives are likely to represent the future agenda for information management.

Current Issues

7.10 Increasingly, professional staff have access to a database that provides clinical or management support and it is possible, within limits, to gather and analyse information about diagnostic related groups, service activity and unmet need at population level. In addition, the use of geo-mapping (linking postcodes to service activity) is enabling more sophisticated needs assessment analyses. However, there are deficits within the current mental health services within Northern Ireland:

- information systems, particularly in secondary care, vary considerably in design and application and are under-developed in some locations;
- information collection and analysis is not clinically driven and may reflect a HPSS market culture;
- staff skills in using currently available information are under-developed;
- record integration and communication within health and social care across boundaries and beyond is highly variable; and
- information currently gathered at a regional level may no longer be fit for purpose.

7.11 These problems are having an adverse impact on the quality of care. No rationalisation of information demands has occurred for more than 20 years and staff feel increasingly disenfranchised in relation to the ownership of information. They perceive a potential disconnection between data analysis and policy and practice. Some information returns are simply not utilised but continue to be collected. There is a growing desire among professional staff delivering care for a greater focus on information gathering that:

- reflects the complexity of health and social care tasks they are engaged in rather than the volume;
- supports staff in the provision of care;
- forms needs assessment and research; and
- informs the evidence base for improvements in care.

Towards a Vision for Information

7.12 Professional staff and service managers require a vision for information and information management that enables them to see the relevance of data gathering and that will support them in their daily work.

7.13 It is proposed that this vision is developed through the production of a comprehensive Regional Information Strategy for Mental Health, with an implementation plan. This strategy must address the following issues:

- outdated data items and methods of collection and terminating their use;
- a minimum data information set, its relevance to clinicians and practitioners and the new framework for data collection;
- the use of the Person Centred Information System (PCIS) to provide the optimum clinical and management information;
- a programme of training that maximises the use of information; and
- information for service users and carers.

7.14 Such a strategy would provide the link between outcome measurement and data collection. It would also give a focus to performance management by clearly identifying critical targets, the timescales for their achievement and the information required to enable decision making on achievement.

7.15 As a first step, it is proposed that the DHSSPS develops a comprehensive understanding of the profile of adult mental health services in Northern Ireland by mapping service provision. This would enable future investment to be targeted towards gaps in the provision of those services identified as critical to achieving the vision of a modernised and properly resourced service. To enable this to happen, service providers must identify a local information provider (LIP) to work with DHSSPS in establishing an accurate and up-to-date information base.

RESEARCH AND DEVELOPMENT

Background

7.16 While the work of the Review has been founded on the best current research evidence on clinical and service effectiveness, there are many gaps in our knowledge base at the present time. High quality research and information is needed on mental health, and mental ill-health and their determinants, effectiveness of interventions and on closing the gap between research information and service implementation of new research evidence.

Local Research and Development

7.17 Within Northern Ireland there have been several recent research investigations into aspects of mental health. However, in the absence of any clear centrally-led strategy for mental health and learning disability there has been no clear vision of research and development needs and no co-ordination of existing research effort. There are notable deficiencies in the range, quality and reliability of information on mental ill-health and service needs for Northern Ireland as a whole. The lack of detailed prevalence information on mental health and learning disability is a particular problem at the beginning of a new strategy for service reform.

7.18 Nevertheless, the time is right for the establishment of a coherent research and development strategy for mental health in Northern Ireland. The Review as a whole covering policy, services, legislation; and including the entire range of service users and carers, provides a strong signal for a Research & Development Strategy to underpin the work of the Review and its implementation. In addition, there have been recent initiatives within Ireland and the UK which provide new opportunities for collaboration and networking for research and development work and for the sharing of new information and new knowledge.

7.19 The National Disability Authority in Ireland has established a Research Advisory Committee to advise on matters pertaining to disability research. It has recently recommended a National Strategy for Mental Health Research to ensure that research in this area is prioritised, commissioned and managed in a collaborative, strategic manner with the participation of the complete range of stakeholders, including service users.

7.20 A Mental Health Research Network has recently been established for England and Wales with a commitment to collaboration across the UK. The development of effective research networks across the UK and Ireland provides timely opportunities not only for research collaboration, support and information sharing but also for the development and delivery of large scale trials and studies necessary to address many of the questions relating to clinical service effectiveness in mental health and learning disability.

A NORTHERN IRELAND RESEARCH AND DEVELOPMENT (R&D) STRATEGY

7.21 The Review recommends the establishment of a broad based R&D Strategy to underpin the Review as a whole and its implementation. The aims of the Strategy are threefold:

- To deliver high quality research and provide quality research information on mental health and learning disability, prioritising areas of greatest need and areas of highest information deficiency. Research information is required on a range of issues including mental health morbidity, the needs of users and carers, effectiveness of current and emerging interventions at both the individual and service levels;
- Closing the gap between research knowledge and service uptake. Research and development initiatives are required to close the existing gap between established research knowledge and service uptake of such knowledge. New initiatives are required to translate research knowledge into health and social care practice at both the individual and service levels and so to contribute to the quality and effectiveness of services and better outcomes for individuals, for carers and families;
- The establishment and contribution to UK and Ireland research networks in mental health and learning disability. This is essential to strengthen the research base, share knowledge, and provide support for the health and social care research community in mental health and learning disability.

7.22 One of the first steps in the development of an R&D Strategy is the establishment of a small Strategy Group with input from both the service side, including user and carer representation, and the academic community. An early requirement of this Group will be to set priorities for research and development. The principal initial funding support for health and social care research is the DHSSPS R&D Office. A first step is the submission of an outline R&D Strategy. This should be followed by a detailed strategy with prioritised project proposals including commissioned research to support new mental health policies and investigator led research. An important aspect of a new Research Strategy will be enhancement of the research capacity in mental health through education and training for young researchers.

7.23 Within Adult Mental Health a number of research priorities are likely to include:

- Specific interventions:
  - detailed information on mental health morbidity and need;

  - outcomes research, including the effectiveness and cost effectiveness under usual service conditions of psychological therapies and psychosocial interventions;
  - service user satisfaction with specific services, including service interventions; and
  - the development of agreed outcome measures.
- Service delivery and organisation:
  - variations in the use of individual services and their impact on service user outcomes including satisfaction;
  - evaluation of organisational changes;
  - investigations into staff morale, retention and performance and their impact on service effectiveness; and
  - assessing the barriers to the implementation of research evidence.
- Service user involvement
  - evaluating service users' views on services and how services can best meet their needs.

7.24 The development aspect of R&D should focus on the barriers to implementation of research knowledge. New roles are likely to be required to support the implementation of research conclusions as part of service improvement at local level.

RESOURCING THE CHANGES

7.25 The programme of change that is required for adult mental health services in Northern Ireland represents major challenges at both regional and local levels. The proposals have major implications for future Health and Personal Social Services Mental Health revenue and capital investment programmes and for future estate requirements. With anticipated reorganisation and reconfiguration local providers must ensure that resources follow service users.

7.26 These changes cannot occur without protected investment from Government to drive local service development. The need for additional investment is justified on a number of well recognised factors:

- socio-economic deprivation in Northern Ireland is significantly higher than in Great Britain;
- the rurality of our population distribution is contributing to higher costs;

- the health of our population is generally poorer compared to Great Britain;
- the link between deprivation and health and social care need is particularly strong in the mental health programme of care;
- the aftermath of the troubles is still being experienced, for example, in terms of mental health problems and needs and this is likely to continue for many years;
- investment levels in mental health services has not kept pace with other areas of the UK and there are significant gaps in service provision; and
- as a result of a general failure to replace or redevelop aging estate and to address a growing backlog across Northern Ireland, a significant capital investment in mental health services is required.

7.27 This situation has arisen in the context of relatively low HPSS management and administrative costs compared with Great Britain. Although hospital productivity has doubled over the last ten years, the model of care in Northern Ireland is accepted to be too reliant on inpatient care. New funding needs to be matched by rigorous performance management at all levels to ensure the introduction of the essential new services and to secure a modern service, fit for the needs of our population in the early part of the 21st century.

7.28 The Review recommends the establishment of a Mental Health Modernisation Programme, essentially a financial plan that brings together the service recommendations of the Strategic Framework and matches them with both the necessary funding streams and the performance milestones that will guide local investment (See Chapter 8).

7.29 The service elements that will require investment include:

- User and Carer involvement and support;
- Advocacy services;
- Independent sector services;
- Mental health promotion;
- Primary care mental health services including Early Intervention;
- Community mental health services including CMHTs, HTTs, ACTs, Crisis Response teams;
- General Hospital Psychiatric Liaison services including A&E services; Perinatal services;
- Crisis services including day hospital care;

- Services promoting recovery including the needs of service users with Challenging Behaviour;
- Dual Diagnosis services;
- Community accommodation;
- Homelessness support;
- Day care including prevocational training and employment;
- Prescribed drugs;
- Psychological Therapy services;
- Specialist services including services for people with eating disorders, people with acquired brain injury or progressive brain disease, personality disorders, psychological trauma, disorders of gender and sexuality, women with perinatal mental health problems, people with AS/HFA and deaf people with mental health needs; and
- Workforce training needs.

7.30 Detailed comparitor work has been undertaken with regional and local adult mental health services in England. Comprehensive and detailed costings have been prepared to advise the DHSSPS of the resource costs necessary to achieve the Strategic Framework.

CHAPTER 8

IMPLEMENTING THE STRATEGIC FRAMEWORK

INTRODUCTION

8.1 This Strategic Framework, incorporating the 10 Standards for service development outlined in Chapter 1, together with the detailed evidence-based recommendations in Chapters 3-6 provides a comprehensive blueprint for realising the new vision for Adult Mental Health Services. In Chapter 7 consideration has been given to the infrastructure requirements of the Service Framework. Consideration must also be given to the processes by which the new Strategic Framework for Adult Mental Health can be realised. Three processes are considered fundamental to successful implementation:

- regional support for change;
- local implementation; and
- performance assessment.

Regional Support for Local Implementation

8.2 The Department of Health, Social Services and Public Safety (the Department) has been generative in establishing the independent Review, responsible for the crafting of this Strategic Framework for Adult Mental Health. The Department has also worked in close partnership with the Review to define and clarify the infrastructure issues on which the Service Framework depends, including workforce, information and costings.

8.3 The Department will play a key role in:

- delivering workforce and information strategies. These strategies are fundamental to the success of the Strategic Framework (see Chapter 7);
- overseeing the roll-out of the Strategic Framework to agreed standards and timescales
- securing funding for resources.

8.4 Implementation should be directed by an Implementation Team which should include user and carer input. Within Health and Personal Social Services organisations, the new Duty of Quality will drive the quality agenda, underpinned by Health & Social Care Governance. The Department must ensure engagement of other Government Departments so that those elements of the Strategic Framework outwith health and social care are delivered both successfully and on time.

8.5 The success of the Strategic Framework depends on many stakeholder groups, the support of Government and the wider public. The Implementation Team with the support of the Department have an important role in facilitating the processes necessary for engagement and communication with all stakeholder groups and for the broad agenda of change management.

Local Providers

8.6 Local providers will ultimately be responsible for ensuring the implementation of the Strategic Framework and must translate it into local delivery plans. This, in turn, requires local partnerships with all relevant statutory and independent providers and a shared vision. Successfully harnessing the energies and resources of the independent sector and of users and carers will be pivotal in realising the vision.

8.7 The Strategic Framework brings a new opportunity for change, with a clear statement of what has to be done and firm performance management. It provides a sound evidence base for action together with examples of good practice.

8.8 Translating the Strategic Framework into effective local implementation arrangements will present significant challenges for professional staff, management and local service leaders. It envisages a broad-based and complex reform of mental health services. It is also occurring in the context of anticipated substantial reorganisation and re-configuration of health and social services and local administration. A major challenge is the change in culture necessary to deliver this Strategic Framework, a culture of partnership, collaboration and empowerment.

8.9 Keeping the perceptions and needs of service users and carers at the centre of our vision will be most important throughout the change process. The involvement of service users and carers can greatly assist the realisation of a new vision and a new culture at local level. Barriers to change must be recognised, identified and overcome. The current interest, commitment and skill of professional staff, service managers and service leaders provide a sound foundation on which to build the local implementation of the Strategic Framework. There is much to be gained by collaborative learning and working across provider groups, sharing examples of good practice, exploring

opportunities for complementary contributions to, in particular, more specialist services, and working opportunities for joint initiatives in staff training.
Good Practice Example (Annex 5.8.1)

8.10 The Strategic Framework provides a unique opportunity to consider the use of learning networks, "communities of practice", self assessment and peer review as models of organisational change and development. Self-assessment combined with external validation by peer teams provide valuable learning opportunities and facilitate multidisciplinary professional development.[182]

ENSURING PROGRESS – PERFORMANCE ASSESSMENT

8.11 The Strategic Framework represents an ambitious agenda for change within adult mental health services, aimed at driving up quality across all aspects of services. In Chapter 1, 10 Standards for service development were identified. Each Standard provides a central pillar of the Strategy around which succinct areas of service development and improvement must be built (see Recommendations). To ensure progress in each of the 10 areas a set of 54 Performance Indicators have been specified and against which progress on implementation can be measured. Performance Indicators can measure:

- inputs to the Strategic Framework, such as the allocation of specific resources;
- processes, such as the establishment of new service elements for improvements within existing services; and
- outcomes, including users' and carers' experience of service, health outcomes, improvements in social functioning.

8.12 Outcomes, including user and carer experience of services, are the ultimate test of service effectiveness. An important objective of the Strategic Framework is the development and implementation of suitable outcome measures of known provenance. Nevertheless, specific service processes, which have an evidence based relationship with outcomes, provide important measures of service quality and effectiveness. Performance indicators, based on process measures, eg the establishment of Crisis Response services, provide a basis for monitoring and evaluating progress on implementation of the Strategic Framework. A set of performance indicators for each Standard are presented in the following Table. The strategic vision, standards and framework within this review of adult mental health, underpinned by a clear implementation plan, together provide a coherent basis for the necessary reform and modernisation of services.

Standard 1. Services to be Person-Centred

Performance Indicators	**Targets**	**Milestones**	**Lead Responsibility**	**Information and Sources**
Providers adopt a planned approach to the whole system of service provision	Whole system strategic plans	Year 1	Local Mental Health Service provider (MHS)	Submission of strategic plans by providers to Commissioners and Department
Service users and carers must be involved in mental health service planning, development and delivery Deliver monitoring	Representative user and carer involvement in planning and development	Year 1	Local MHS provider	Local Information Provider (LIP) confirmation
	y, Monitoring and Evaluation	Year 2		
	Comprehensive infrastructure to support users & carers	Year 2		
Service vision, plans and strategy must be needs-driven.	Local assessment of need	Year 1	Local MHS provider	LIP confirmation

Standard 2. Effective Community and Primary Care Services

Performance Indicators	Targets	Milestones	Lead Responsibility	Information and Sources
Primary care mental health services must have service users and carers involved in development, delivery and monitoring of services	Service user and carer participation on Local Primary Care Groups	Year 2	Local Primary Care Group (LPCG)	LPCG confirmation
Primary care team access to a named mental health professional	Named mental health professional	Year 1	Local MHS provider	LPCG confirmation
Screening Perinatal arrangements for perinatal mental health	screening	Year 2	LPCG	LPCG confirmation
Multidisciplinary protocols for medication for management for depression	Agreed protocols depression	Year 2	LPCG	LPCG confirmation
Access to high standards of psychological support and therapies	Therapists have assured levels of qualification and supervision	Year 5	LPCG	LPCG confirmation
	Agreed access to psychological therapies. – 50% Y – 100%	ear 7 Year 12	LPCG and local MHS provider	LPCG confirmation

Standard 3. Effective Community Mental Health Services

Performance Indicators	Targets	Milestones	Lead Responsibility	Information and Sources
CMHTs must be adequately staffed with a range of health and social care professionals	30 care staff per 100,000 adult population	Year 3	Local Mental Health Service providers	LIP confirmation
	50 care staff per 100,000 adult population	Year 7		
People with complex and enduring mental illness offered yearly assessment by CMHT	Annual assessment completed for 80% of service users	Year 3	Local MHS provider	LIP confirmation
	Annual assessment completed in 90% of service users	Year 5		LIP confirmation
Provision of services for people with dual diagnosis	Needs assessment completed	Year 3	Local MHS provider	LIP confirmation
	Strategy for people with dual diagnosis	Year 5		
Mental health services for people in acute hospital settings including A&E	Liaison service needs defined by each acute hospital	Year 2	Acute services providers	LIP confirmation
	Agreed services established	Year 5	Acute service providers	
Meeting the physical health needs of people with complex and enduring needs	Locally agreed protocols	Year 2	Local MHS provider and LPCG	LIP confirmation

Standard 3. *Continued*

Performance Indicators	Targets	Milestones	Lead Responsibility	Information and Sources
Effective Tier 2 services for people with eating disorders, acquired brain injury or progressive brain disease, deaf people with mental health needs, mental health needs arising from psychological trauma, personality disorders, people with Asperger's Syndrome or high functioning autism, disorders of gender and sexuality, for women at risk of mental disorder including relapse or recurrence of serious mental disorder in the perinatal period	Locally agreed protocols	Year 5	Local MHS provider	LIP confirmation

Standard 4. Effective Crisis Services

Performance Indicators	Targets	Milestones	Lead Responsibility	Information and Sources
Evidence-based Home Treatment Services 50% established for each Provider's catchment area	HT services established for of catchment area	Year 1	Local MHS provider	LIP confirmation
	HT services established for 100% of catchment area	Year 3		
Day hospital, step-up and step-down ser residential established services established within each provider area	Day hospital or step-up vices	Year 3	Local MHS provider	LIP confirmation
	Day hospital and step-up services established	Year 8		
Inpatient Services	Review of Inpatient provider Services	Year 1	Local MHS and DHSSPS	LIP confirmation
	Business Case for Acute Inpatient and for Challenging Behaviour Services prepared	Year 2	Local MHS provider	
	Agreed inpatient provider facilities established	Year 10	Local MHS	LIP confirmation

Standard 5. Promoting Recovery

Performance Indicators	Targets	Milestones	Lead Responsibility	Information and Sources
The needs of those with complex and enduring mental health needs should be clearly defined for each Provider catchment area	Needs assessment completed for SMI	Year 1	Local MHS provider	LIP confirmation
Community services for promoting recovery established by each MH service provider	Community recovery services	Year 3	Local MHS provider	LIP confirmation
Assertive Community Treatment teams established for service users with highest level of disability and vulnerability	ACTs established – coverage 50% – coverage 100%	 Year 3 Year 4	Local MHS provider	LIP confirmation
In addition to meeting the equality obligations under Section 75 of the Northern Ireland Act 1998, service users' specific communication, cultural, spiritual and religious needs recognised and acknowledged	Culture sensitive information and communication provision Information accessible to people with a learning disability	Year 2 Year 2	Local MHS provider	LIP confirmation
Comprehensive advocacy services	Accessible independent advocacy services	Year 2	Local MHS provider	LIP confirmation

Standard 5. *Continued*

Performance Indicators	**Targets**	**Milestones**	**Lead Responsibility**	**Information and Sources**
Separate age - appropriate services for younger people with a first episode of psychosis	First episode services – coverage 50% – coverage 100%	 Year 3 Year 5	Local MHS provider	LIP confirmation
Services for people with mild learning disability	Local assessment of need Local service agreement in place	Year 1 Year 2	Local MHS provider	LIP confirmation
Local arrangements for people growing older with enduring or relapsing mental illness	Local needs assessment Local service agreements in place	Year 1 Year 2	Local MHS provider	LIP confirmation
Services for people with challenging behaviour	Needs assessment completed Low secure provision strategy agreed In-patient and community provision in place	Year 2 Year 3 Year 5	Local MHS provider	LIP confirmation
Tier 2 services for people with acquired brain injury or progressive brain disease; people with Asperger's Syndrome or high functioning autism	Locally agreed protocols	Year 3		

Standard 6. Sustaining Meaningful Lives

Performance Indicators	Targets	Milestones	Lead Responsibility	Information and Sources
People with complex and enduring needs should be provided with appropriate provider opportunities for education, training and occupation	Occupational assessment including yearly review – 50%	Year 1	Local MHS	LIP confirmation
	– 80%	Year 3	Local MHS provider	LIP confirmation
	A comprehensive range of occupational services	Year 5	Local MHS provider	LIP confirmation
	Vocational specialists provider appointed	Year 5	Local MHS	LIP confirmation
	A comprehensive range of day care services	Year 5		
A comprehensive range of accommodation for people with severe and – enduring mental health needs	Discharge protocols for accommodation needs		Local MHS provider	LIP confirmation
	50%	Year 1		
	– 80%	Year 2		
	– 100%	Year 3		
	Choice of accommodation appropriate for need		DSD	LIP confirmation
	– 50%	Year 5		
	– 90%	Year 10		
Exemption to the single room rent for people with complex and enduring needs	Exemption provision	Year 2	DSD	DHSS&PS

Standard 6. *Continued*

Performance Indicators	**Targets**	**Milestones**	**Lead Responsibility**	**Information and Sources**
Exemption from prescription charges for people with complex and enduring needs	Prescription exemption	Year 2	DHSSPS	DHSS&PS
Provision of intensive suppor support for those wishing to get back to work	Intensive t – 50% – 70% – 90%	Year 3 Year 5 Year 10	Local MHS provider and DEL	LIP confirmation

Standard 7. Providing for People with Special Needs

Performance Indicators	Targets	Milestones	Lead Responsibility	Information and Sources
A tiered strategy for people with eating disorder	Needs assessment Regional Y strategy	Year 1 ear 2	DHSSPS	DHSSPS
A tiered strategy for people with acquired brain injury or progressive brain disease	Needs assessment Regional strategy	Year 2 Year 3	DHSSPS	DHSSPS
A tiered strategy for deaf people with mental health problems	Needs assessment Regional Y strategy	Year 2 ear 3	DHSSPS	DHSSPS
A tiered strategy for people with Asperger's Syndrome or high functioning autism	Needs assessment Regional strategy	Year 2 Year 3		
A tiered strategy for psychological services including services for people with psychological trauma and psychosexual disorders	Needs assessment Regional strategy	Year 2 Year 3	DHSSPS	DHSSPS
A tiered strategy for people with personality disorder	Needs assessment Regional strategy	Year 2 Year 3	DHSSPS	DHSSPS
A tiered strategy for women with mental health problems in the perinatal period	Needs assessment Regional strategy	Year 2 Year 3	DHSSPS	DHSSPS

Standard 8. Meeting the Information and Support Needs of Service Users, Carers and Families

Performance Indicators	Targets	Milestones	Lead Responsibility	Information and Sources
Existing policy and legislation relating to users and carers	Implementation of existing policy and legislation		Local MHS provider	LIP confirmation
	mostly implemented	Year 2		
	fully implemented	Year 5		
Information and education for users and carers	Basic information education and support	Year 1	Local MHS provider	LIP confirmation
	Comprehensive information, education and support	Year 3		
Carers should be offered an annual assessment and a written care plan	Annual assessments and written care plans		Local MHS provider	LIP confirmation
	partly implemented	Year 3		
	fully implemented	Year 5		
Providers should make available support for appointed carers including dedicated carer and family workers	Carer and family workers		Local MHS provider	LIP confirmation
	partly implemented	Year 3		
	fully implemented	Year 5		
Suitable hospital visiting arrangements for families including children	Visiting arrangements for families		Local MHS provider	LIP confirmation
	partly implemented	Year 3		
	fully implemented	Year 5		

Standard 8. *Continued*

Performance Indicators	**Targets**	**Milestones**	**Lead Responsibility**	**Information and Sources**
Agreed protocols between children's and mental health services for children requiring protection	Protocols agreed Protocols partially implemented Protocols implemented fully	Year 2 Year 3 Year 5	Local MHS provider	LIP confirmation

Standard 9. Ensuring Sound Information for Mental Health

Performance Indicators	Targets	Milestones	Lead Responsibility	Information and Sources
Baseline information on current services	Baseline information	Year 1	Local MHS provider	LIP confirmation
Mental health information strategy (MHIS)	Agreed MHIS	Year 1	DHSSPS	DHSSPS
Agreed Indicators for roll out of MHIS	To be agreed	To be agreed	DHSSPS	DHSSPS
Development and implementation of agreed mental health outcome measures including A measures appropriate for people with special needs	Agreed outcome measures for use in secondary care services	Year 2	DHSSPS	DHSSPS
	greed outcome measures for use in specialist services	Year 3	DHSSPS	DHSSPS
	Incorporation Y of clinical outcome measures into PCIS and supported in routine clinical practice	ear 5	DHSSPS	DHSSPS
User and carer evaluation of services	Baseline user and carer evaluation completed	Year 1		
	User and carer evaluation of services implemented at local provider level	Year 2		
	User and carer re-evaluation of services	Year 3, Year 7, Year 10		
A Northern Ireland R&D Strategy for adult mental health services	Agreed first phase of R&D Strategy (Years 1-5)	Year 1	DHSSPS	DHSSPS

Standard 10. Delivering an Effective, Competent and Confident Workforce

Performance Indicators	Targets	Milestones	Lead Responsibility	Information and Sources
A comprehensive workforce strategy for adult mental health	Agreed strategy	Year 1	DHSSPS	DHSSPS
A strategy for workforce recruitment	Strategy implementation targets to be agreed	To be agreed	DHSSPS	DHSSPS
A strategy for multidisciplinary training skilling appropriate for CMHTs, rehabilitation, other community teams and hospital based staff	Agreed strategy for workforce Implementation targets to be agreed	Year 1 To be agreed	DHSSPS DHSSPS	DHSSPS DHSSPS
Agreed strategy for psychological therapies training including the requirements for psychological trauma, eating disorder and psychosexual disorder	Agreed strategy for psychological therapies Implementation targets to be established	Year 1 To be agreed	DHSSPS DHSSPS	DHSSPS DHSSPS

ANNEX 1

STEERING COMMITTEE MEMBERSHIP

Chair – Professor David Bamford, University of Ulster

Deputy Chair - Professor Roy McClelland, Queen's University, Belfast

Mrs Martha McClelland, Mind Yourself

Mr Martin Daly, LAMP

Mrs Marie Crossin, CAUSE

Mr Winston McCartney, Northern Ireland Association for Mental Health (NIAMH)

Reverend Trevor Williams

Dr Raman Kapur, Threshold

Dr Paschal McKeown, MENCAP

Dr Fred Browne, Chair, NI Division, Royal College of Psychiatrists

Dr Oliver Shanks

Ms Eileen Sherrard, Down Lisburn HSS Trust

Mr Nevin Ringland, PRAXIS

Mrs Maureen Ferris, EHSS Board

Mrs Mary O'Boyle, Holywell Hospital

Mr Patrick Convery, Gransha Hospital

Mr Leslie Frew, DHSSPS

Professor Tony McGleenan, University of Ulster

Mr Brendan Mullen, Ulster Community and Hospitals HSS Trust

Professor Alan Ferguson, Northern Ireland Association for Mental Health, (NIAMH)

Mr Brian Dornan, Causeway HSS Trust (and latterly SHSS Board)

Mr Mark Timoney, DHSSPS (and latterly SHSS Board)

Dr John Owens, Cavan/Monaghan Community Mental Health Project

Professor Geoff Shepherd, Cambridgeshire & Peterborough Mental Health Partnership NHS Trust

Mr Colin Beck, City of Edinburgh Council

Miss Joanne McDonald, Buzz Advocacy Group

Dr John Hunter, Department of Education

Master Brian Hall, Master of Care and Protection

Mrs Siobhan Bogues, ARC (NI)

Detective Superintendent Andrew Bailey, PSNI

Ms Moira Davren, Royal College of Nursing

Dr Diana Patterson, Shaftesbury Square Hospital, Belfast

Mrs Marian Nicholas, Carer Representative

Dr Walter Boyd, GP, Clogher (until September 2003)

Professor James Scott Brown, University of Ulster (Replacing Dr Walter Boyd from December 2003)

Mr Bill Halliday, Equality Commission (NI)

ANNEX 2

TERMS OF REFERENCE

1. To carry out an independent review of the effectiveness of current policy and service provision relating to mental health and learning disability, and of the Mental Health (Northern Ireland) Order 1986.

2. To take into account:
    - the need to recognise, preserve, promote and enhance the personal dignity of people with mental health needs or a leaning disability and their carers;
    - the need to promote positive mental health in society;
    - relevant legislative and other requirements, particularly relating to human rights, discrimination and equality of opportunity;
    - evidence - based best practice developments in assessment, treatment and care regionally, nationally and internationally;
    - the need for collaborative working among all relevant stakeholders both within and outside the health and personal social services sector;
    - the need for comprehensive assessment, treatment and care for people with a mental health need or a learning disability who have offended or are at risk of offending; and
    - issues relating to incapacity.

3. To make recommendations regarding future policy , strategy, service priorities and legislation, to reflect the needs of users and carers.

EXPERT WORKING COMMITTEES

FIRST WAVE

- ### Social Justice and Citizenship:
  Convenor: Bill Halliday, Equality Commission for Northern Ireland
  To consider relevant legislative and other requirements, particularly relating to human rights, discrimination and equality of opportunity; and how best to promote the social inclusion of people with a mental health problem or leaning disability and their carers, taking account of employment, housing, education, social security, personal finance and other social issues.

- ### Legal Issues:
  Convenor: Master Brian Hall, Office of Care and Protection
  To include a review of the Mental Health (Northern Ireland) Order 1986; the Mental Health Commission; the Mental Health Review Tribunal; the procedures for the transfer of patients to and from Northern Ireland; issues relating to people who are not able to look after their own property and affairs as a result of a mental health problem or learning disability; and issues relating to people with a mental health problem or a learning disability who are in contact with the criminal justice system.

- ### Learning Disability:
  Convenor: Siobhan Bogues, Manager, ARC (NI)
  To review policy and services for children and adults with learning disability.

- ### Adult Mental Health:
  Convenor: Professor Roy McClelland, Deputy Chair of the Review
  To include consideration of primary care provision, acute services, rehabilitation and community care for adults with a mental health problem.

SECOND WAVE

- ## Mental Health Promotion:

  Convenor: Professor Alan Ferguson, Chief Executive, Northern Ireland Association for Mental Health

  To include consideration of how best to promote positive mental health in society, with particular reference to the impact of the recently-published Mental Health Promotion Strategy, and how best to meet the needs of people at risk of suicide.

- ## Child and Adolescent Mental Health:

  Convenor: Moira Davren, Royal College of Nursing

  To include consideration of primary care provision, acute services, rehabilitation and community care for children and adolescents.

- ## Dementia and Mental Health Issues of Older People:

  Convenor: Nevin Ringland, Chief Executive, PRAXIS Care Group

  To include consideration of primary care provision, acute services, rehabilitation and community care for older people with dementia or a mental health problem.

- ## Alcohol and Substance Misuse:

  Convenor: Dr Diana Patterson, Shaftesbury Square Hospital

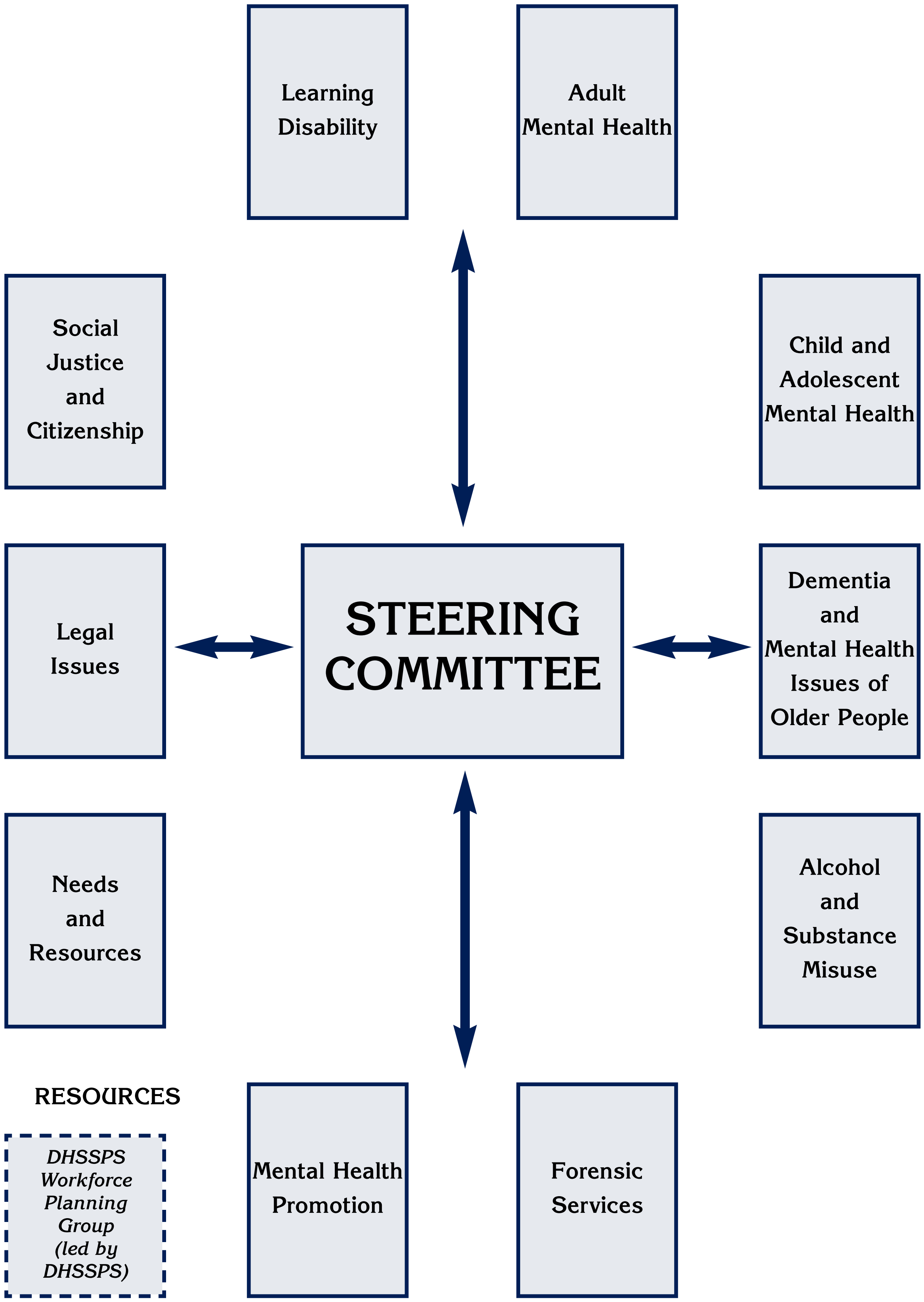
  To include consideration of the links between mental health and alcohol and substance misuse, and the provision of the most appropriate assessment, treatment and care for those involved.

- ## Forensic Services:

  Convenor: Dr Fred Browne, Chair, Northern Ireland Division, Royal College of Psychiatrists

  To consider the assessment, care and treatment of people with a categorical mental illness, severe personality disorder or who engage in dangerous or persistently challenging, aggressive behaviour, and who may be in contact with the criminal justice system.

EXPERT WORKING COMMITTEE STRUCTURE



ANNEX 4

ADULT MENTAL HEALTH WORKING COMMITTEE

Brendan Armstrong
David Bamford
Desi Bannon
Walter Boyd
Diana Cody
Peter Colvin
Liz Cuddy
Maxine Cresswell
Marie Crossin
Martin Daly
Jayita Deodhar
Brian Dornan
Alan Ferguson
Victoria Greenwood
Stephen Guy
Bill Halliday
Molly Kane
Michael Kelly
Seamus Logan
Carolyn Maxwell
Roy McClelland (Convenor)
Arthur McClean
Brian McCrum
Graeme McDonald
Ian McMaster
Maria McManus
Maureen McParland
Mary O'Boyle
John Owens
Diana Patterson

In addition, the following assisted the work of the Review , providing papers on specific themes:

Clare Adams
David Bolton
Marie Goss
Billy Gregg
Richard Ingram
Chris Kelly
Gerry Lynch
Janine Lynch
Maria O'Kane
Oliver Shanks
Eileen Sherrard
Brian Symington
Janice Thompson
Ken Yeow

GOOD PRACTICE EXAMPLES

CHAPTER 3

5.3.1 **Rural Support.** A local example of good practice is in the farming community, where use of a telephone helpline and a rural Health Action Zone has been of benefit to many. (Contact: 0845 6067607)

5.3.2 **Creggan estate, Londonderry, partnership approach to Health promotion.** This project demonstrates that statutory/community partnerships, accompanied by proper planning and long term commitment, work effectively, even in areas of high social disadvantage. Professional boundaries can be reduced, and a more open and flexible approach to health and social needs adopted. (Contact: 028 71373870)

Croydon Social Prescribing Scheme. Social prescribing schemes are increasingly recognized as effective in dealing with early signs of stress and psycho-social difficulties. In this Scheme, GPs have established a partnership with the voluntary and community sector, and employed a community worker based at a health centre. Practice staff refer patients to this worker, who has extensive knowledge of local community and voluntary services.
(Contact: www.mindincroydon.org.uk)

5.3.3 **Both the University of Ulster and Queen's University** have recently invested in the appointment of full time staff dedicated to supporting the mental health well-being of staff.
(Contact: QUB 028 90245133 and UU 028 90366336).

5.3.4 **City of Toronto Mental Health Services.** This is an example of explicit funding arrangements combining statutory and voluntary sectors. A mixed economy of care is practiced, with clear definitions of responsibility and accountability in allowing planned and timely delivery of targeted care. All mental health service providers, including the local hospital, have entered into formal legal agreements to create a highly accessible system for the consumer, based on the strengths of each of the partner organisation.
(Contact: www.toronto.cmha.ca).

5.3.5 **Limavady Pilot Project.** The pilot review of referral pathways and the use of a senior skill professional based in primary care has led to reductions in log jamming of referrals, improvement of morale and development of timely, accessible assessment services. Audits of satisfaction have shown enthusiasm for continuing the service from service users, primary care staff and secondary care staff. (Contact: 028 77722123).

The Mid Ulster Primary Care Mental Health Project. This began in June 2002. The aim of the project is to provide a primary care based mental health service offering brief therapies to patients of 45 General Practitioners within 16 surgeries. Early evaluations showed high levels of acceptability to service users and practitioners with a significant demand for extension of the service. (Contact: 028 86747250).

5.3.6 **The Northern Ireland Association for Mental Health** offers contract based 24 hour counselling services to staff groups both within the health and social services sector and other employers. The Carecall Counselling Service (Contact: 028 90245821).

5.3.7 **Lenadoon Counselling Service, West Belfast.** This service is under the guidance of a management panel of local community representatives, a Clinical Psychologist, a Consultant Psychiatrist and a General Medical Practitioner. A number of trained counsellors provide focused counselling interventions to a population that has experienced a substantial burden of civil disturbance and socio-economic deprivation. This service is highly valued by the local community, by local statutory providers and by General Medical Practitioners. (Contact: 028 90585544).

The Primary Care Counselling Service, Armagh. This counselling service, established in 2000, provides for people with: mild to moderate depression with a first time diagnosis, delayed or unresolved post-natal depression, acute bereavement, Post Traumatic Stress Disorder, anxiety disorders, panic disorders, health anxiety, low self-esteem, stress, interpersonal difficulties. The Service has been a very effective and successful initiative, not only in clinical efficacy, but in reduced referral figures to the Community Mental Health Teams and in admission rates. It has also prevented a number of mental health problems developing into more serious disorders. The successful outcomes led to a request to expand the service to the Dungannon area, and in conjunction with the local Health and Social Care Group the service is being extended to this area. (Contact: 028 37522037).

5.4.1 **Homefirst Crisis Response (CR) Service.** This Trust-wide service was established in April 2003 for people experiencing a mental health crisis that could have the potential to result in an admission to hospital. The CR team comprises nursing, social work, medical professionals and support workers. The CR team offers a multi-disciplinary approach to care and a single point of access for referral agents.

The objectives are to:

- Offer a rapid, 24 hour response and assessment service for patients referred with mental health difficulties who present to the service in crisis
- Provide a flexible, accessible service which will work alongside existing to enhance the care and treatment of people with a mental health crisis
- Support carers and families of those with mental illness in crisis
- Work alongside primary and secondary care to provide a more seamless service for users
- Support general hospital facilities in providing assessment and advice for those who present with mental health problems.

In its first year, the team accepted 2903 appropriate referrals. The team was able to maintain approximately 90% of those who presented in the community, and achieved a reduction in hospital admissions of 39% compared with the year before the service was introduced. (Contact: 028 9040 2038)

Newcastle Crisis and Treatment (CAT) Service is based on a Crisis Response and Home Treatment model with high fidelity to five key components:

- Provision of 24/7 access – in this team, the night shift is only two people but they are on-site, not on-call (demand for home treatment beyond 6.00 pm is described as very low).
- Involvement until resolution of the crisis – this can range from a few days to several weeks.
- Multidisciplinary care – the key components are seen as medicine, nursing, social work and occupational therapy.
- Team mobility – they must be able to assess in a variety of locations at any time and usually within two hours or sooner
- Gatekeeping of admission to places in psychiatric acute hospital – to ensure achievement of the overall goal, the home treatment of psychiatric crises.

A crucial part of the operation of the team is a triage arrangement with all referral agents. Once someone is identified as being in need of an urgent assessment (at risk of significant harm to self or others or at risk of hospital admission), they are seen by a team member, assessed and a decision made on the management of their care and treatment. The aim is to offer home based treatment if at all possible, based on a partnership with carers and the imaginative use of whatever resources can be brought to bear on the situation. The CAT team currently consists of 34 staff serving a catchment population of 460,000. Operating now for three years they have had a significant impact on inpatient requirements with a fall from 30 adult places/60,000 to a planned requirement next year of 20/60,000. (Contact 0191 370 7760)

Useful information on crisis resolution/home treatment can be obtained from the Department of Health's NSF Policy Implementation Guide (www.doh.gov.uk/NSF/mentalhealth.htm).

5.4.2 **Anam Cara, Birmingham** offers stays of up to three weeks for people referred by home treatment teams or for former guests who self-refer. This is a user-led initiative providing an alternative crisis service to hospital admission. In an evaluation by the Sainsbury Centre most residents had a diagnosis of schizophrenia. All those interviewed felt the service had met all their needs (Contact: 01213841344).

5.4.3 **Ards Mental Health Day Hospital.** The Ulster Community and Hospitals Trust Mental Health Day Hospital, a purpose-built unit opened in 1989 adjacent to the Inpatient and Outpatient Units, was recently awarded the Charter Mark for its work.

Staffing: Nurses – four full-time and one part-time
Occupational Therapists – two full-time, two part-time and one OT technician
Complementary Therapist – one part-time.

The Day Hospital, which has 40 places, receives 6-15 referrals each week. It functions both as an alternative to admission for patients in the Community, as well as facilitating early discharge from inpatient care. Each service user has an individual plan of care co-ordinated by a named health professional. Each user is assessed prior to admission and treatment is regularly reviewed by the multidisciplinary team.

The Unit is open Monday – Friday and facilitates many individual and group activities outside working hours. In addition to individual programmes of care and therapy there are a number of group activities: Patient advocacy service, Job Clinic, Carers' Group.

Future plans include extending the opening hours from 9.00 am – 9.00 pm seven days a week and providing a base for the Crisis Intervention Team. (Contact: 02891 56115)

5.4.4 **Slievegrane Centre, Downpatrick.** The Centre, recently awarded Charter Mark and Environmental awards, aims to provide a service for people with severe and enduring mental illness. It consists of a six bed residential unit with four supported flats, staffed 24 hours. There are also 7 supported group homes and outreach is provided to individuals who have moved on from the service to independent living. The philosophy of the service is empowerment and normalisation. Residents are encouraged to see the unit as a home and to live as independently as possible, whilst engaged in a structured, tailored rehabilitation programme. The staff team consist of two psychiatrists (one consultant, one staff grade), a unit manager, 8 residential workers, 2 care assistants, 1 consultant clinical psychologist, 1 social worker and 1 occupational therapist. Very positive results have been achieved since opening of the unit in 2000, with many residents moving on to independent living (Contact: 028 4483 9959).

The Cavan/Monaghan Rehabilitation/Recovery Team. This team, established in 1998, takes referrals only from the mental health service. The core philosophy is to provide individualised care for service users and carers based on identified needs and implemented as much as possible in a non-institutional setting. Referrals are made through the team co-ordinator and discussed at weekly team meetings. The protocol for patient care includes: referral, assessment, programme implementation, programme review. Care plans are drawn up by relevant team members once assessments are completed, involving, where possible, the service user. The multidisciplinary rehabilitation/recovery team takes referrals only from within the mental health service and are made through the team co-ordinator and discussed at weekly team meetings. (http://www.monaghanmodel.com/implications.htm).

5.4.5 **Cavan/Monaghan Project.** The Assertive Outreach Team is a component part of the community rehabilitation/recovery team and consists of 11 Assertive Outreach nurses. They take responsibility for all new referrals to the Community Recovery Team. The locus of care for Assertive Outreach is primarily in the patient's home (http://www.monaghanmodel.com/implications.htm).

5.4.6 **Windsor First Episode Service.** This service, based at Belfast City Hospital, was established in 2000 for young people (18-30 years) living within the South Belfast catchment, experiencing a first episode of psychosis. The service consists of a multi-disciplinary, multi-agency team from the Belfast City Hospital Trust, South & East Belfast Community Trust, School of Nursing Queen's University, voluntary and independent sectors including care and user participation. The aim is to provide an up-to-date evidence based range of services including family intervention, social skills development, medication management, cognitive behavioural therapy and family intervention. (Contact: 028 90 32 9241 ext 2518)

West Midlands IRIS Group have produced guidelines and a 'tool-kit' for the development of Early Intervention Services (www.iris-initiative.org.uk).

5.4.7 **Foyle Health and Social Services Trust** have proposed a new psychological therapies service model within their strategic review of adult mental services (2003). They propose a 21 person Psychological Therapy Team, composed of a number of different professional groups, whose members have expertise in the range of psychological assessment, formulation and intervention skills. The team will be brought together from existing and newly appointed staff (Contact: 028 71314201).

5.4.8 **THORN.** A notable educational initiative in recent years has been the creation of THORN courses at Queen's University and the University of Ulster. These courses provide training for a range of professionals in psychosocial interventions for people with severe mental illness. (Contact: QUB 028 90335742 and UU 028 90366336)

The Meriden Project in the West Midlands Region provides in-service, multidisciplinary training aimed at increasing access to evidence-based psychosocial interventions. It is funded by the West Midlands NHS executive and involves training across 17 Trusts within the region in family intervention. A cascade model of training was implemented with trainers being trained in each Trust to run courses and act as supervisors. To date, more than 1500 therapists from all disciplines have been trained and carers' experience of the mental health service in the region has been transformed. (Contact: 0121 6235500)

5.5.1 **Southwest London and St. George's Mental Health NHS Trust:** In this service OTs act as clinical vocational leads, working with specialist services to increase access to employment and education for clients. There is a vocational support worker on each team. Prior to intervention > 60% clients SMI group were not engaging in any work, education or structured activity. This reduced to 20% after 1 year's experience on the programme. 888 people have specific vocational input in the period from Nov. 01 – Nov. 02. After 1 year 469 were involved in open employment. This scheme is mainstreamed within the Trust, and is being piloted in six different sites across Europe over a three-year period. (Contact: 0208 682692.)

Avon & Wiltshire Mental Health Partnership NHS Trust, Work Development Team. The existing OT service was re-profiled and a model developed to assist people remain in work and re-enter the workforce after a period of mental illness through re-deployment or retraining. The team developed partnerships with local FE colleges, voluntary services and New Deal provisions. Standardised assessment tools are used. Since it inception in 2000, until Jan 2003 over 550 Occupational Action Plans have been completed. 250 people have returned to full-time employment. A job retention service has been developed. Primary evaluation confirms that the JRT is delivering considerable benefits to stakeholders who include, clients, employers and GPs. Key factors in the provision of an effective service were identified; early intervention, a focus on return to work, ongoing support, access and role of case manager. It is recommended that a national network of job retention services should be developed and a longitudinal evaluation conducted. This is a NHS Beacon Service and is now being replicated in over 60 Healthcare Trusts in UK. (Contact: 01179633681.)

Pentreath Industries – Employment Project: Registered charity providing "gateways to employment for people with or recovering from mental ill health in Cornwall" 4 main areas of service delivery: training, employment placement advice, social, firm development and raising awareness of mental health issues. 76 staff provided long-term support for 598 service users in 2000, referred from community mental health teams. An average of 30 people per year move into full-time waged employment. A wide range of opportunities and options are on offer, including 4 social firms.
(Contact: The Sainsbury Centre 0207 403 8790.)

Down & Lisburn Trust has appointed a full-time Senior OT with a specific remit for vocational rehabilitation in the mental health team. They are the only Trust in Northern Ireland to have a specialist vocational mental health post. The postholder works in partnership with Action Mental Health (ACCEPT) (Contact: 028 92665141 ext.2336.)

Causeway Trust has a full-time Senior I with a similar remit. This post is based at the Pavestone Centre, a recently established social enterprise. Although funded through the physical disability programme, the post holder also deals with clients with an SMI diagnosis. Plans have been proposed to develop a vocational assessment and supported employment service at Pavestone. No funding source as yet identified. (Contact: 028 70347875.)

WELL Project:- Well being, Education, Learning and Living Project
This initiative aims to provide a sustainable support service, linking existing statutory and voluntary services, to enable people with enduring mental illness to access a wide range of learning activities, which will enhance quality of life, personal development, skills, opportunities for achievement, social inclusion and reduce stigma. (Contact: 028 44613311 ext. 3292.)

5.5.2 **Clare House Enniskillen** has a six-bedded attached unit, where people with mental health crisis may come for unplanned respite. The unit is staffed by nursing and an Occupational Therapist with consultant back-up. Residents are encouraged to be as independent as possible and prepare their own food and attend to their personal needs with support from staff.
(Contact: 028 6632 6361).

5.5.3 **Homefirst Trust** in partnership with M.U.S.T. hostel in Cookstown provides one bed as an alternative to hospital admission to those to those who have been assessed suitable. This unit is staffed by voluntary sector staff on a 24-hour basis and receive support from the Crisis Team as appropriate.
(Contact: 028 9040 2038).

5.5.4 **First-Step Move-On Accommodation.** There are many examples of statutory hostels across Northern Ireland providing first step move-on accommodation with intensive rehabilitation as a stepping-stone to supported or independent accommodation. Staff come from nursing, social work or NVQ trained background and are supported by Community Psychiatric Nurses, Mental Health Social Workers and consultants or senior registrars. Examples are Norfolk Court Hostel, Rathenraw, Antrim (028 9442 8089); Kintyre Park

Hostel, Ballykeel, Ballymena (028 2565 3755); and Ballymacoss Hostel, Lisburn (028 6632 6362).

5.5.5 **Stamford Avenue, Herts.** A registered mental health nursing home providing client support for people with learning disabilities, mental health needs and/or challenging behaviour. The project is registered to take people detained under the Mental Health Act. It provides intensive support with nursing and project workers and is supported by a Registered Medical Officer and a multidisciplinary team (Contact: 01763 236 167).

5.5.6 **North and West Belfast** under their Health Action Zone have set up a Care Co-ordinator Service for single homeless people in North and West Belfast. The service assists single homeless people and rough sleepers to enhance their health status. (Contact: 02890 755434).

Health and Homeless Guidance (Scottish Executive). There are 15 health and homelessness action plans across Scotland covering each NHS Board area. Discharge protocols have been agreed in many areas, which have ended the practice of people being discharged from hospital without accommodation. Innovative and effective interventions have been developed to encourage health screening for rough sleepers; an example of this is offering veterinary checks for dogs of rough sleepers.
(Contact: 0131 2445132).

5.5.7 **Belfast Homeless Support Team** and hostel, has had a major impact on the homeless mentally ill in the Belfast area. (Contact: 02890 238091).

5.5.8 **Northern Ireland Association for Mental Health Advocacy Service.** The key features of this model are:

- Independence with appropriate funding
- Training and relevant experience
- Good communication skills
- Good understanding of mental health services and legislation
- Ability to empower patients to speak for themselves
- Acceptance and support by professional staff
- Advocacy at the macro level in relation to policy and planning of services
- Advocacy with individual service users

- Access to appropriate administrative information
- Accountability and evaluation
- Education of patients and staff on the nature of the advocacy process.

(Contact: 028 9032 8474).

5.5.9 **C.A.U.S.E.,** a Northern Ireland carers' and families' organisation, provides a broad model of support for carers which includes a helpline, self-help groups, carer advocates, training and education programmes and the representation of carers' views. (Contact: 028 9023 8284).

RETHINK is a national organisation providing support for both service users and carers. Its programme includes self-help groups, training and education, carer advocacy, and the representation of carers' views. It has an informative and useful web-site. (Contact: 028 90402323).

5.5.10 **CESP (Carer Education Support Programme).** A collaboration between Rethink and the Sainsbury Centre. Held over 3 months, this course is co-led by trained carers and mental health professionals. It gives information about schizophrenia and skills training in problem solving, assertiveness, communication and managing symptoms. (Contact: 028 90402323).

PREP (Programme for Relatives: Education and Partnership), developed by Dr. Carole Castles from C.A.U.S.E. with funding from the Mental Health Foundation. The programme aims to alleviate feelings of subjective burden in relatives, to increase their knowledge of serious mental illness and to enable them to improve their quality of life. It is facilitated by trained, experienced carers and has input from mental health professionals.
(Contact: 028 9023 8284).

5.5.11 Professionals trained in the multidisciplinary **Thorn programme** are greatly valued by carers and families. **The Meriden Project** in the West Midlands has expanded this model of support to a very favourable response from carers. (Contacts as at Example 5.4.8 above)

5.5.12 **FACE,** a Northern Ireland organisation, has developed a local programme of support for young carers in the area of mental illness.
(Contact: 028 3833 2261)

Barnardo's Young Carers Project in the Northern Health and Social Services Board area, deals with families with a parent with a disability, including those with mental health problems. They offer the young person counselling, group support, peer support and recreational opportunities, and take a holistic family approach. (Contact: 028 2564 8809).

CHAPTER 6

5.6.1 **Down and Lisburn Trust Community Brain Injury Team.** This team comprises a group of professionals who adopt an interdisciplinary approach in addressing the community based services promoting recovery and reintegration needs of people with acquired brain injury. The team works with the person with brain injury, their families and carers. (Contact: 028 92663572)

5.6.2 **Redford Court, Toxteth, Liverpool.** This is a supported living facility for people with ongoing emotional and behavioural problems, who require intensive support to maintain community living. The facility is run by the Brain Injury Rehabilitation Trust. The Trust offers a range of services for people with brain injury, including residential assessment, rehabilitation and training, transitional living units, individual outreach options and long term care. Each of these services is supported by a specialist multidisciplinary clinical team. (Contact: 0151 2808181).

5.6.3 **Forster Green Hospital Ward / Joss Cardwell Unit.** Provides multidisciplinary inpatient and outpatient brain injury rehabilitation. Plans are ongoing for the development of a purpose built 25 bedded unit on the Musgrave Park Hospital site. (Contact: 028 90793681).

5.6.4 **York House, Brain Injury Rehabilitation Trust, York.** A neurobehavioural service for acquired brain injury. York House is a 14 bedded neurobehavioural rehabilitation unit which provides an intensive neurobehavioural assessment and rehabilitation service for individuals with severe mood disturbance and challenging behaviour following acquired brain injury. The unit specialises in the management of people with challenging behaviour and is able to take referrals for people detained under the Mental Health Act. All clients have access to an intensive programme of rehabilitation and recreational activity, which seeks to restore independence as far as possible. Staffing levels are high and for some people a programme of one to one support is available. (Contact: 01904 412666).

Robert Ferguson Unit, Royal Edinburgh Hospital, Edinburgh Healthcare NHS Trust. This unit is the National Neurobehavioural Rehabilitation Unit for Scotland. It addresses the needs of those people who suffer severe behavioural complications after acquired brain injury. It operates on the basis of a multidisciplinary team, which a high staff-patient ratio and provides slow stream rehabilitation in preparation for community reintegration and continuing care. (Contact: 0131537 6214).

The Kemsley Unit, St Andrews Hospital, Northampton. Provides specialised rehabilitation for adults with non-progressive acquired brain injury, with challenging behaviours, including physical aggression, who are excluded from conventional rehabilitation settings. In addition, physical, emotional and cognitive and other behaviour problems may be present. The service offers a continuum of care ranging from secure facilities and highly structured rehabilitation, hospital based transitional living, community based transitional living and case management for individual clients. (Contact: 01604 29696).

5.6.5 **Nottingham and Bristol** are developing locally based Mental Health Services for deaf people.
(Contact: Nottingham 0115 948 3268 and Bristol 0117955 6098).

5.6.6 **Link Centre, Eastbourne** – provides specialist rehabilitation to deafened adults through intensive rehabilitation programmes. (Contact: 01323 638230).

RNID (NI) Rehabilitation Project – initially targeting people deafened as a result of Northern Ireland Troubles. (Contact: 02866 329849).

5.6.7 **Manchester Metropolitan University** run a five-year distance learning Masters of Arts in Social Work with deaf people. This course is open to both hearing and deaf students. (Contact: 0161 247 2112)

The University of Salford's Deaf People's Access to Nurse Education Project has created an educational environment that has enabled deaf people to become qualified mental health nurses. (Contact: 0161 295 2769)

5.6.8 **Sandyford Initiative in Glasgow.** This project provides drop-in services for transpeople. It has received a very high level of approval by its clientele. Such initiatives may be directly transferable to appropriate locations in Northern Ireland, but due to the small numbers of transpeople, the maintenance of a co-ordinating central service would remain vital for preserving experience and expertise in relation to treatment. (Contact: 0141 211 8137)

CHAPTER 8

5.8.1 **Getting Better Together.** Trent & Northern Yorkshire NHS and the Northern Centre for Mental Health jointly commissioned this Mental Health Collaborative. The aim of the project was to improve service users' experiences of acute inpatient care and achieve better outcomes throughout the process of admission, stay and discharge. The collaborative placed an emphasis on joint working to achieve mutually desirable results. It has made a significant move away from "the hero-innovator" towards a more empowering means of creating sustainable change through the utilisation of shared perspectives of jointly owned goals." There is clear evidence that the collaborative has been successful in improving service users' experience of acute inpatient psychiatric units and achieving better clinical outcomes." Hugh Griffiths, Clinical Lead Mental Health Collaborative. (Contact 0191 370 7760).

BACKGROUND ON SERVICES FOR PEOPLE WITH SPECIAL NEEDS, DISCUSSED AT CHAPTER 6

6.1 Services for People with Eating Disorders

The Nature and Extent of the Issues

6.1.1 Eating disorders include anorexia nervosa, bulimia nervosa and the atypical eating disorders such as binge-eating disorder. Obesity may be an associated problem. They can lead to severe physical and psychosocial complications and are associated with significant levels of co-existing psychiatric conditions.

6.1.2 The National Service Framework for Mental Health recognises the potentially serious nature of eating disorders. [1] The Royal College of Psychiatrists has highlighted the need for specialist services and the lack of service provision in many parts of the UK. [2,3] The National Institute of Clinical Excellence (NICE) has recently produced treatment guidelines, setting standards for service delivery.[4]

6.1.3 Within Northern Ireland, the DHSSPS has made the development of eating disorders services a recent priority.[5,6,7] A Regional Eating Disorders Working Group (REDWG) has been in operation to oversee this work. The membership of the group represents the interests of service planners, providers, users and carers.

6.1.4 The estimated prevalence of anorexia nervosa is 6-30 per 60,000 population and of bulimia nervosa is 60 per 60,000 population. The approximate incidence of anorexia nervosa is 4-6 per 60,000 population per year and of bulimia nervosa is 6-30 per 60,000 population per year.[8,9] There is a suggestion that at least as many people present with an atypical eating disorder.[1] A significant number do not seek help for a variety of reasons including denial, shame and the lack of appropriate services being in place.

6.1.5 Using the above figures, it is estimated that in Northern Ireland there would be around 170-510 cases of anorexia nervosa and 1700 cases of bulimia nervosa existing at any one time, and approximately 68-170 new cases of anorexia nervosa and 170-510 new cases of bulimia nervosa per year. The additional service users who suffer from atypical eating disorders as well as those who are not currently seeking help need to be taken into account when planning services.

6.1.6 As part of a local needs assessment, the REDWG commissioned qualitative research which sought the views of carers, sufferers and service providers.[10] The key recommendations arising from this address the problems with awareness and early detection, primary care intervention, the paucity of integrated and equitable specialist services, as well as the need for good health promotion strategies.

6.1.7 The current lack of specialist services in Northern Ireland is evident. Most service users are managed within primary care and generic adult and child and adolescent mental health teams. Voluntary groups play an important role in supporting service users and carers. A specialist outpatient clinic had offered a geographically limited (Greater Belfast) service and received around 12 referrals per month, but the recent retirement of the Consultant in charge has meant that it is now closed to new referrals.

6.1.8 Inpatient interventions may be necessary due to medical/psychiatric emergencies or for more intensive psychotherapeutic intervention. The former group tend to be admitted to local general medical/psychiatric units and one survey suggested that this demand was around 9.5 beds per year. As there is no local specialist inpatient unit, the latter group are sent for treatment outside Northern Ireland, which can be very difficult for the service users as there is separation from their families. These extra-contractual referrals are costly e.g. within the Eastern Health & Social Services Board (EHSSB) in the financial year 2003/2004, 9 patients were sent to England at a cost of around £500,000 (EHSSB, personal communication).

6.2 Services for People with Acquired Brain Injury or Progressive Brain Disease

The Nature and Extent of the Issues

6.2.1 There is growing recognition of the mental health needs of adults with neurological conditions affecting higher cerebral functions, including non-progressive acquired brain injury (e.g. arising from trauma, haemorrhage, anoxia, infections, toxins including alcohol, nutritional deficiency, epilepsy) and progressive brain disease (e.g. Multiple Sclerosis, Parkinsons Disease, Huntington's Disease, early onset Dementias).

6.2.2 Such neurological conditions can lead to a range of impairments in physical functioning (e.g. spasticity, disturbance of gait, sensory impairment), cognitive functioning (e.g. poor concentration, distractibility, failure to learn, rapid forgetting, poor planning and social judgement, difficulties in the understanding of language and in verbal expression) and emotional and behavioural functioning (e.g. anxiety, depression, personality change, irritability).[11] Impairments in functioning can result in reduced independence in personal care and activities of daily living (e.g. hygiene, dressing, cooking, cleaning). They frequently impact negatively on social and family relationships and upon the individual's ability to return to work or engage in socially meaningful activity. [12, 13, 14, 15]

6.2.3 A significant number of people with acquired brain injury and progressive brain disease will have significant and continuing health care needs over a long period of time. [16] Local research estimates the prevalence of people with moderate and severe psychological and physical disability following traumatic brain injury and subarachnoid haemorrhage to be 66 per 100,000 and suggests that the presence of moderate and severe psychological impairment is the best predictor of long term social disability. [17]

6.2.4 Cognitive, emotional and behavioural deficits post injury are key predictors of negative outcome in terms of recovery, rehabilitation and community reintegration. These determine the extent to which an individual is able to adapt to his/her changed functioning and develop a positive quality of life. [18]

6.2.5 People with acquired brain injury and progressive brain disease are at greater risk of mental health problems, particularly depression, anxiety and psychosis. These can go undiagnosed and untreated, impacting negatively on morbidity and mortality. Estimates of incidence and prevalence of various mental health conditions vary widely, reflecting differing definitions adopted in studies. [19-24]

6.2.6 Families of people with acquired brain injury or progressive brain disease suffer considerable emotional distress and burden, which can have a considerable impact on their own mental health. They are at greater risk of mental health problems than the general population. Family stress is associated with coping with personality and behavioural change in a relative, often in addition to coping with physical and cognitive impairments. [25-29]

6.2.7 A biopsychosocial approach to understanding and managing the emotional and mental health problems associated with acquired brain injury or progressive brain disease is essential. [30] A range of treatment options, both pharmacological and psychological, are developing to address mental health needs. [31-34]

Service Provision

6.2.8 In general, the therapeutic interventions, rehabilitation and long-term support needs of people with acquired brain injury and those with progressive brain disease are addressed through separate services. Service planning tends to be separate and in recent years service development has focused narrowly on traumatic brain injury.

6.2.9 At present there is limited provision to meet the mental health needs of people with acquired brain injury or progressive brain disease. Needs are addressed through local mental health services and liaison psychiatry at the Royal Victoria Hospital, Belfast. The mental health needs of adults below 65 years of age with progressive conditions are addressed by older adult mental health services.

6.2.10 Two specialist mental health services operate at a Board/Regional level, but are currently under-developed.

6.2.11 **A Neuropsychiatry Service based at Belfast City Hospital.**
This is mainly an outpatient service, providing both new patient assessment and review clinics. A liaison service is also provided, receiving tertiary referrals, predominantly from psychiatry, neurology and neurosurgery. This service addresses the mental health needs of people with acquired brain injury and progressive brain disease.

6.2.12 **Maine Neurobehavioural Unit, based in Knockbracken Healthcare Park, South & East Belfast Trust.**
This unit has developed to address the needs of people with acquired brain injury or progressive brain disease, who have severe and persistent problems. The unit provides short-term admissions for assessment, slow stream rehabilitation/recovery and long-term care for those whose behaviour cannot be met in other settings. The unit has provided a focus on the subgroup of those with acquired brain injury and progressive brain disease, who present with severe challenging behaviours. It has demonstrated the utility of a multidisciplinary approach in providing a therapeutic environment, individual behavioural management and skills development programmes.

6.2.13 Community brain injury teams play a significant role in addressing mental health needs, although their remit is broader. These teams are at various stages of development within the physical disability programme of care in each of the Boards. They have developed as part of the continuum of rehabilitation and community reintegration services required to meet the needs of people with acquired brain injury. A core aspect of their work is in the assessment, treatment and ongoing management of cognitive, emotional, social and behavioural needs. Given their training and expertise in these areas, clinical neuropsychologists have played an important role in the leadership and development of these teams. An important function of these teams is assessment of need and service development.

6.2.14 A number of non-statutory services provide support to carers, social reintegration programmes, pre-vocational and vocational skills training and supported living. The work of these organisations involves attention to the psychological needs of their clients.

6.2.15 Consultation with service users and carers, local service providers and individual professionals, highlights a number of problems with current service provision in addressing the mental health needs of people with acquired brain injury and those who have progressive conditions. Local experience is consistent with reports concerning service provision and mental health needs throughout the United Kingdom. [35, 36]

6.2.16 A number of common issues arise:

- **Service Requirements.** There is a lack of appropriate residential and supported living options, with appropriate expertise and levels of staffing to deal with emotional and behavioural problems. There is also a lack of ability within services to respond rapidly to crisis situations in the community and a lack of support for families and carers.
- **Specialist Support to Local Services.** There is at present a lack of adequate levels of specialist expertise to support local services dealing with emotional and behavioural problems.
- **Training Needs of Staff.** There is a need for greater education of staf with regard to the emotional, cognitive, behavioural and mental health needs of people with acquired brain injury and progressive brain disease. Lack of awareness of patient vulnerability can lead to poor care planning, inappropriate placements, lack of adequate support, crisis situations and poorly-managed risk.

- **Services Responsibility.** Situations can arise where there is lack of clarity regarding responsibility in terms of local versus specialist services, or where there is co-morbidity, or where an individual's needs cut across programmes of care.

Good Practice Examples

Down & Lisburn Trust Community Brain Injury Team. This team comprises a group of professionals who adopt an inter-disciplinary approach in addressing the community rehabilitation and reintegration needs of people with acquired brain injury. The team works with the person with brain injury, their families and carers.

(Contact: 028 92663572).

Redford Court, Toxteth, Liverpool. This is a supported living facility for people with ongoing emotional and behavioural problems, who require intensive support to maintain community living. The facility is run by the Brain Injury Rehabilitation Trust. The Trust offers a range of services for people with brain injury, including residential assessment, rehabilitation and training, transitional living units, individual outreach options and long term care. Each of these services is supported by a specialist multidisciplinary clinical team. (Contact 0151 2808181).

York House, Brain Injury Rehabilitation Trust, York. York House is a 14 bedded neurobehavioural rehabilitation unit, which provides an intensive neurobehavioural assessment and rehabilitation service for individuals with severe mood disturbance and challenging behaviour following acquired brain injury. The unit specialises in the management of people with challenging behaviour and is able to take referals for people detained under the Mental Health Act. All clients have access to an intensive programme of rehabilitation and recreational activity, which seeks to restore independence, as far as possible. Staffing levels are high and for some people a programme of one-to-one support is available.

(Contact 01904 412666).

Robert Ferguson Unit, Royal Edinburgh Hospital, Edinburgh Healthcare NHS Trust. This unit is the National Neurobehavioural Rehabilitation Unit for Scotland. It addresses the needs of those people who suffer severe behavioural complications after acquired brain injury. It operates on the basis of a multidisciplinary team, which a high staff-patient ratio and provides slow-stream rehabilitation in preparation for community reintegration and continuing care. (Contact: 01315376214).

The Kemsley Unit, St Andrews Hospital, Northampton. This unit provides specialised rehabilitation for adults with non-progressive acquired brain injury with challenging behaviours, including physical aggression, who are excluded from conventional rehabilitation settings. In addition, physical, emotional, cognitive and other behaviour problems may be present. The service offers a continuum of care ranging from secure facilities and highly structured rehabilitation, hospital based transitional living, community based transitional living and case management for individual clients. (Contact: 01604 29696).

6.3 Services for Deaf People with Mental Health Needs

The Nature and Extent of the Issues

6.3.1 It is estimated that 1 in 7 of the general population has some degree of hearing loss.[37] Between 1 in 600 and 1 in 1500 people are profoundly deaf from early life. Although more than 90% are born into hearing families, many grow up to use Sign (British Sign Language, BSL or Irish Sign Language, ISL) as their first or preferred language, and identify themselves as members of the Deaf Community. Deaf children, particularly those in hearing families, can face many obstacles during development. The diagnosis of deafness may be delayed, though the advent of neonatal screening should address this.

6.3.2 The UK Government has recognised British Sign Language as a language in its own right in Great Britain. Similar formal recognition of both BSL & ISL was announced by Paul Murphy, Secretary of State for Northern Ireland on 29th March 2004. This is an important development for the deaf community.

6.3.3 Digital hearing aids, cochlear implants and, vitally, opportunities for early access to sign language should prevent the significant and potentially permanent language delays and deprivations characteristic of the recent past. Many deaf adults have had limited educational opportunities and may have poor literacy, which limits their access to written information, including television subtitles.

6.3.4 **Deaf People and Mental Health.** Deaf people encounter the same range of mental health problems as the general population. However, they are also at increased risk of having complex and organic disorders, as many of the non-genetic causes of deafness, such as maternal rubella, neonatal jaundice, prematurity, birth anoxia and meningitis, can be associated with a range of physical, sight and neurological problems.

6.3.5 A significant minority of deaf people are deaf/blind and their mental health needs are also complex.[38] Psychiatric illnesses such as schizophrenia[39] and affective disorders are the same in deaf as in hearing people, but are associated with difficulties in diagnosis.[40]

6.3.6 The developmental difficulties and social pressures affecting many deaf children give rise to an excess of emotional, behavioural and adjustment problems (40-50% compared with 25% for the general population) which can continue into adult life.[41, 42]

6.3.7 **Mental Health Services for Deaf People.** Deaf people, particularly sign language users, have considerable difficulty in gaining access to health promotion programmes and the whole range of medical services. There are, however, some good examples of good practice in this area.

Good Practice Example

Deaf Connection recognised that traditional methods of health promotions were not reaching members of the deaf community effectively and what was required was to work directly with deaf people to identify their health needs and prepare programmes to tackle these. Training and support are provided to enable workers with deaf people to deliver a range of health programmes to the deaf community. (Contact: 0141 4202820)

6.3.8 Prelingually deaf people experience unacceptable rates of mis-diagnosis and unjustified long-term admission in psychiatric hospitals, often without their informed consent, and are additionally afforded inappropriate treatment. Appropriate treatment is dependent upon diagnosis, which in turn is dependent upon accurate communication.[43]

6.3.9 **Communication.** Adequate communication is essential for effective mental health assessment and treatment. Sign language interpreters are essential if clinicians do not sign. Even so, a service user's signing may be poorly developed, idiosyncratic or affected by mood or thought disorder. An interpreter can only say if effective communication is not taking place – he or she is not trained or empowered to assess or comment on a person's signing. Deaf professionals in mental health services, therefore, are the most appropriate people to facilitate or assess communication in these circumstances.

Good Practice Examples

National Deaf Services, South West London & St George's Mental Health NHS Trust, London. (Contact: 020 86826925

National Centre for Mental Health & Deafness, John Denmark Unit Manchester. (Contact: 0161 772 3400)

National Deaf Mental Health Services, Denmark House, Queen Elizabeth Psychiatric Hospital, Birmingham. (Contact: 0121 678 2005)

RNID Community Support Worker, Ulster Community and Hospitals Trust. RNID (NI) in partnership with Ulster Community and Hospitals Trust employs a Deaf Community Support Worker to support deaf people with mental health problems and learning disabilities in the community. (Contact: 02890 239619)

6.4 Services for People with Psychological Trauma

The Nature and Extent of the Issues

6.4.1 This area of need has been identified within the Review because of the rapidly growing knowledge about the impact of traumatic events on individuals and families, the increasing awareness of the consequences of chronic trauma-related disorders and the implications for services, and the particular circumstances in Northern Ireland associated with the civil conflict. Further, the clinical experience in treating trauma-related disorders has contributed to the body of knowledge and skills in both statutory and independent services, as has the development of specialist services that have been established to address both Troubles and non-Troubles related trauma.

6.4.2 Over the last fifty years there has been significant progress in understanding the mental health implications of exposure to life-threatening or other traumatic experiences. There have also been developments in our knowledge of the longer term effects on well-being, economic and social functioning, and significant developments in assessment and treatment. Development and progress in policy, training, the purchasing and delivery of services in relation to psychological trauma, can and should make important contributions to the mental and wider health of the community. In the context of the civil discord and violence of the period since the late 1960's in Northern Ireland, a developing political context has permitted public discourse on the impact of the violence, and local studies suggest that there are significant needs arising from the civil violence to be addressed.

6.4.3 Exposure to traumatic experiences can lead to the development of a range of mental health problems, including post traumatic stress disorder (PTSD), depression, specific phobias, personality disorders such as borderline personality disorder, and panic disorder[44], PTSD defines a group of signs and symptoms that often occur together, forming an identifiable pattern that characterises a recognisable disorder. It is often accompanied by other psychological or mental health problems, such as substance abuse and depression[45] (co-morbidity). Together these characteristics will usually induce levels of distress and disablement. This may, in turn, lead to dysfunction in social, occupational and relationship terms, and the exercising (or omission) of key life choices (based on the helpful appraisals arising from a traumatic experience) that have a long term bearing on the person and his or her family.

6.4.4 Key to understanding the levels of need arising from psychological trauma is knowledge about:

- the level of exposure to traumatic experiences;
- the incidence of psychological trauma following exposure; and
- the rate of recovery.

6.4.5 Whilst the Troubles in Northern Ireland have helped to draw attention to the needs arising from traumatic experiences, it is important to remember that citizens suffer from traumatic experiences which are found in technologically developed societies and which are not associated with political conflict. Accidents (including perhaps most strikingly road traffic accidents), assaults (including child abuse and sexual assault) and other traumatic experiences, such as those associated with suicide or serious illnesses, are well understood to give rise to risks of post trauma psychological implications for those who experience them.

6.4.6 The needs of children (and of adults) who have suffered and continue to suffer psychological and other health-related needs arising from childhood traumatic experiences, including abuse, represent a particular professional challenge. In the terms of the Children (Northern Ireland) Order 1995, children and young people considered to have suffered such experiences, and who as a result have post trauma-related problems, could be deemed to be *children in need*.

6.4.7 The needs of adult survivors of childhood sexual abuse who suffer enduring traumatic reactions and the consequences of their experiences on their development into adulthood are increasingly being recognised and understood. Progress in the development of treatments, the way services are provided, support for partners and other supports (including the contribution of self-help services) and the strategic arrangement of services, need to be maintained and built upon, and shaped by emerging knowledge about the needs of those affected by such experiences.

6.4.8 The relationship between childhood sexual abuse and subsequent mental ill-health problems has been extensively studied and found to be a risk factor for a wide range of disorders of mental health in adult life. Adults who have experienced sexual abuse as children are more at risk of developing anxiety, depression, self-destructive behaviour, self-harm and suicide. Combined sexual and physical abuse is a significant risk factor for adult trauma symptoms, including post traumatic stress disorder. Up to two thirds of people who suffer from eating disorders have a history of sexual abuse [46] Particularly among women, physical and sexual abuse are risk factors for substance misuse including alcohol misuse.[47]

6.4.9 The Heather Report[48] included proposals in relation to:

- Access to appropriate services
- Greater clarity about how and where to access services
- Increasing the level of services available for the current demand
- Greater service co-ordination

6.4.10 The Mental Health Foundation recommend that adults with a history of childhood sexual abuse in contact with mental health services should be offered counselling or psychotherapy as part of therapeutic intervention regardless of diagnosis. The benefits of a group work approach have also been reported. [49]

Good Practice Example

In 1997 the **Western Health and Social Services Board** established an Interagency Group on sexual abuse involving statutory and voluntary agencies working with adult survivors of childhood sexual abuse. The group has been successful in establishing a training programme for people working with adult survivors of sexual abuse. In addition to a directory of services, a website offering details of services available and advice for survivors has been established. (Contact 028 6632 0046)

6.4.11 The Western InterAgency Group in their detailed review of the needs of those who have suffered childhood experiences of abuse drew attention to the needs of those suffering long term consequences. Trust and confidence were identified as particularly important dimensions of the experience of seeking, securing and accepting help. Psychological and mental health services featured as a major area of need, with clear messages emerging from the Report as to the form services should take issues related to accessibility including the costs of non-statutory services, continuity, integration and referral matters.

6.4.12 Kessler and colleagues,[50] who reported upon a major study into the prevalence of PTSD in 1995, concluded, "PTSD is a highly prevalent lifetime disorder that often persists for years. The qualifying events for PTSD are also common, with many respondents reporting the occurrence of quite a few such events during their lifetimes." Among adult Americans aged 15 to 54 years the estimated lifetime prevalence of PTSD is 7.8%, with women (6.4%) twice as likely as men (5%) to have PTSD at some point in their lives. A number of other epidemiological studies have reported on similar findings.[51-54]

6.4.13 Kessler and colleagues found that the most frequently experienced traumas were:

- witnessing someone being badly injured or killed;
- being involved in a fire, flood, or natural disaster;
- being involved in a life-threatening accident; and
- combat exposure.

6.4.14 Other studies have reported on the incidence of development of PTSD after exposure to traumatic events. Green[55] reported an overall incidence of 25% of individuals exposed to traumatic events. In relation to rape, Figley[56] reported between 35% and a striking 92%. Norris[57] found an incidence of 69% in a sample of 600 people exposed to traumatic events. Breslau and colleagues [58] found that the rate of PTSD in those who were exposed was 23.6%. The variation across studies might, in part at least, be due to the changing definitions of PTSD in the 1980s and 1990s and the severity of exposure in some of the studies. Nonetheless, the findings point to significant consequences.

6.4.15 **Recovery from PTSD and the Implications for Treatment.** Kessler's work is also important as it endeavours to describe the recovery rate from PTSD. In short, 40% of sufferers recover (without treatment) by about 30 months after onset of symptoms. At the other extreme, 35% sufer enduring (and what could be taken to be lifetime) PTSD.

6.4.16 **PTSD Risk Factors.** In on overview of a number of studies of PTSD, Brewin, Andrews and Valentine [59] identified three risk factors for PTSD consistently across all studies, namely, psychiatric history, history of childhood trauma and family history of psychiatric disorders. Specific studies point to other pre-existing personal and social circumstances, and post trauma appraisals and coping as also being related to the development or presence of PTSD.

6.4.17 **The Impact of the Troubles.** Of the work that has been carried out in this field, a number of relatively recent studies provide a view of what the impact might be. In a secondary analysis of a nationally representative population survey conducted in 1997, O'Reilly and Stevenson [60] concluded that "The Troubles are a separate and additional [public health] burden and therefore contributes significantly to the higher psychological morbidity in Northern Ireland", and "It is probable that mental health has been significantly affected by the Troubles."

6.4.18 In The Cost of the Troubles Study, [61] the researchers concluded that about 30% of those who participated and who had been exposed to violence associated with the Troubles had needs approximating to PTSD. This finding seems high and might be associated with the methodology used in the study. Cairns and colleagues [62] found that the mean GHQ scores of a sample of 600 adults from across Northern Ireland was 6.05, which was in line with the findings of an earlier study. That study had detected similar or higher rates of psychiatric disorder to that found in inner city London. Cairns and colleagues concluded, "the ceasefires have not led to any notable change in overall levels of psychological well-being in the Northern Irish population".

6.4.19 One Troubles-related incident has been the subject of needs assessment and casts some light on the impact of a single incident. The Omagh bombing of August 1998 killed 29 people and two unborn children. Over 400 were injured, of whom 135 were seriously injured. In the course of the three and a half years following the bombing, over 670 people were seen by the Omagh Trauma and Recovery Team, which was established in the wake of the bombing by the local health and social services provider, the Sperrin Lakeland Trust. In addition, an unknown, but probably very large number of people were provided with support from a range of primary care, mental health, voluntary and occupational health related services.

6.4.20 A major community study (a needs assessment) commissioned by the Sperrin Lakeland Trust (unpublished) suggests that 7 out of 10 of those who were in the immediate vicinity of the Omagh explosion suffered PTSD. The Sperrin Lakeland Staff Study (a needs assessment) revealed that of those staff who were exposed to work associated with the response to the bombing, 38% of staff had developed PTSD in the period 4-17 months after the bombing. [63]

6.4.21 **The implications.** The following key points emerge from the above discussion:

- 25% (minimum) of those exposed directly to traumatic experiences will have developed PTSD;
- for some types of traumatic events the risks of developing PTSD are much higher;
- 8% of the young adult population will experience PTSD in their lifetime;
- whilst 40% of those who develop PTSD will recover to (at least) below threshold levels within about 30 months, a further 35% will have PTSD in the (very) long term.

6.4.22 The above analysis suggests that psychological trauma has, most probably not been sufficiently recognised as a specific health issue, and, by extension, that needs have not been addressed. Further, clinical experience shows that people with PTSD are thought to have other mental (and sometimes physical) health conditions ie instead of PTSD and are treated on that basis, or the link between mental illness and trauma is not made. This results in long-term treatment programmes because the underlying trauma is not being identified and addressed. In the context of the Troubles and the development of post conflict initiatives to build and consolidate a non-violent society, the legacy of the psychological consequences should be faced and addressed as a special public health issue.

6.5 Services for People with Personality Disorders

The Nature and Extent of the Issues

6.5.1 Personality Disorders exact a heavy burden on affected individuals and on wider society. [64, 65] These are common and distressing conditions, prevalent in 1 in 6 of the adult community population and most commonly in those aged 25 to 44, equally among males and females in their child-rearing years. Estimates may be higher in those with learning disability. [66]

6.5.2 These people experience a wide range of psychosocial problems, including high rates of family disharmony, violence, crime, unemployment and homelessness, early unnatural deaths from suicides and accidents, high rates of associated rates of mental illness and worse outcomes for all illnesses, leading to high service utilization and the revolving door phenomenon. [67] They often present in crisis and in danger to themselves or others and are high users of primary care and mental health services. [68 69] Their children can suffer significantly as a result. [70]

6.5.3 In mental health settings, people with Borderline Personality Disorder (BPD) attract most clinical attention, and where 11-20% of psychiatric outpatients may have this disorder. [71] It is strongly associated with co-morbid substance misuse, anxiety and depressive disorders, unexplained medical conditions and eating disorders and has a 9% suicide rate. [72, 73, 74] Psychological autopsy of suicides of individuals with personality disorder suggests that all may have had at least one mental disorder, and were chiefly a depressive syndrome disorder, substance misuse or both. [75]

6.5.4 Personality disorders are generally recognised as derived from within a stress diathesis model of causation. [76] Studies show that genetic vulnerability and early childhood adversity are potent risk factors for the development of personality disorder in adulthood. [70, 77] In adulthood, exposure to frightening and traumatic events may cause change and damage to the personality. [64]

6.5.5 Mental health professionals have a long-standing ambivalence towards the management and treatment of these disorders. Often these people may be regarded as difficult to treat because of lack of awareness of the condition and availability of treatment options. Typically, they present in chaos and often find traditional treatment options either not readily available or difficult to utilize. Inappropriate interventions can even make their situation worse. [76] Brief inpatient admissions can be beneficial.[74] The process of managing the disorder can be taxing for all concerned.

6.5.6 The presence of severe mental illnesses such as schizophrenia and bipolar disorder with personality disorder is common and is one of the most frequent dual diagnoses found in clinical care. Between 36 and 67 % of those with psychotic disorders have a personality disorder[78] and the proportion tends to be higher in inpatient populations.[79]

6.5.7 The outcome for people with a personality disorder as well as mental illness is generally worse than for those with single mental state disorders, with less improvement in symptoms, poorer quality of life and greater dissatisfaction with treatment after 2 years.[80, 81] The dual diagnosis is often not recognised in ordinary practice and thus may lead to poor reliability of assessment in psychotic disorders.[82, 83] A local survey suggests it may be under-recognised in the psychiatric population by as much as a factor of four.[84]

Treatment of Personality Disorder

6.5.8 There is no evidence that personality disorder is untreatable. However, there is no evidence that all personality disordered people would be treatable if only clinicians' attitudes were right and there were enough resources.[84] Present evidence indicates that mild and moderate degrees of personality disorder are treatable with appropriate interventions.[96, 85, 86] These are usually a combination of psychotherapy (psychoanalytic, psychodynamic, cognitive (CBT) and behavioural and dialectical behaviour therapy (CBT combined with Zen practice)) and pharmacological interventions delivered by clinical teams with experience and training.[87, 88]

6.5.9 Treatability may be a function of service availability.[86] People with personality disorders appear to achieve and maintain better outcomes in treatment in specialist services dedicated to care. The process of rejection and failure to identify the pathology itself affects the treatability of the condition, so that each negative encounter makes the condition worse. Some evidence exists that where specialist therapy is offered and completed, the costs are offset by the subsequent reduction of service usage by people with personality disorder.

6.5.10 Most individuals who present with the diagnosis of personality disorder have more than one personality disorder with a predominant type. Different interventions may be indicated for different types of personality disorder.[89]

6.5.11 Psychotropic medications, particularly SSRIs and mood stabilisers, are useful adjuncts to treatment in the management of people with personality disorder.[88, 90] There is a growing body of evidence for the use of the psychotherapies in the treatment of personality disorders, particularly those of borderline type.[91] In a randomised controlled trial of an 18 month psychoanalytically-led day service for people with BPD, significant improvements in symptoms and social functioning were found and maintained at 18-month review.[92, 93] There is some evidence that Cognitive-Behavioural therapy may also be relatively effective in the treatment of these disorders.[94] Dialectic Behavioural Therapy (DBT) has been shown to be effective in the treatment of BPD.[95] A randomised controlled trial of 18 weeks' psychiatric and psychotherapeutic day treatment with 8 month follow-up for people with affective and personality disorders, has shown improvement in social adjustment at the end of treatment.[96]

6.5.12 Lees et al concluded that "there is accumulating evidence of the effectiveness and particular suitability of a therapeutic community model to the treatment of personality disorder, and particularly severe personality disorder".[87]

6.5.13 Those with personality disorders are heavy users of treatment services throughout the NHS. A number of studies have shown that appropriate psychotherapeutic intervention can change Health Service utilisation by people with Severe Personality Disorder before and after inpatient psychosocial treatment.[97, 98] In one study carried out at the Cassel Hospital, using psychosocial and therapeutic community treatments for up to 18 months, use of inpatient and outpatient psychiatric and inpatient medical and surgical usage was significantly less in the post-treatment group, and there was an average per annum saving of £7423 per patient (May 1992 costs). The Henderson Hospital, an inpatient therapeutic treatment with an average length of stay of 7 months, showed that the cost of treatment for patients was recouped in under 2 years[99] through reduced Health Service utilisation. Therapeutic community provision at Regional District levels can offset the costs of acute psychiatric admissions in the 3 years post follow-up.[100]

Current Services

6.5.14 In England, there are currently 60 Therapeutic Communities provided for by statutory and voluntary sectors. 17% of Trusts have a dedicated service for personality disorder, often day hospital or outpatient programmes, 40% have some level of services and 28% have no service at all.

6.5.15 In Northern Ireland, there are no services dedicated to the management and treatment of people with personality disorder. Within general adult psychiatric provision there are isolated attempts at good practice. For example, at South Belfast Day Hospital and Old See House Day Hospital, North Belfast, consultant psychiatrists involved in the care of day patients are analytically trained and provide psychoanalytic / psychodynamic understanding to other staff working with people with BPD or Co-morbid Personality Disorders.

6.5.16 For many years, those involved in the more specialised provision of services for people with eating disorders, addictions and forensic services have recognized the importance of associated personality disorders in the treatment and prognosis of those with mental illness. However currently, they are unable to offer specific treatments to those people who also have a Co-morbid Personality Disorder.

6.5.17 It is likely that the incidence of personality disorder in Northern Ireland is as high, if not higher, than throughout the rest of the UK. Risk factors are increased by the impact of 35 years of trauma, low socio-economic status and increasing numbers of single parent families.

6.5.18 The lack of resources for the management and treatment of severe mental illnesses such as schizophrenia and bipolar affective disorder has meant that those with a personality disorder are viewed as low status patients and do not access readily the limited resources available to people attending psychiatry, psychology and psychotherapy services in Northern Ireland.

6.5.19 The limited development of psychological services in Northern Ireland (psychiatry, psychology and in particular psychotherapy services) has contributed to a limited understanding of the development of personality disorder, its management and treatment. There are no Therapeutic Communities and no-one is trained in Dialectical Behaviour Therapy in Northern Ireland.

Good Practice Examples

Halliwick Unit, Tottenham, London. Comprising a day unit and intensive outreach service, this Unit offers a treatment service tailored to the specific needs of people with severe personality disorder. A package of group and individual treatment is offered within a day hospital over 5 working days, or within an intensive outpatient programme involving three sessions per week. Patients are offered a self-booking psychiatric clinic to discuss medication and a rapid response in emergencies. Engagement of the patient is important and assertive outreach is included in the programme. (Contact: www.halliwick.nhs.uk or 020 8442 6528.)

Winterbourne House, Reading. A therapeutic community as an intensive treatment programme. The district psychotherapy service draws from a catchment population of 800,000, takes 400-500 referrals per year from primary and secondary care and offers therapeutic community work of 18 months to 6%. Outpatient individual psychoanalytic or dynamic treatment for 2 years or group therapy for up to 3 years is ofered to others for whom treatment is deemed suitable.

The unit was cited in the 2003 NIMHE "Personality Disorder: No Longer a Diagnosis of Exclusion" policy guide, as a "Notable Practice Site". Service user involvement has always been a guiding principle in the therapeutic approach used, and several of the service users and ex-users participated in the user consultation exercise for the NIMHE guide. It is at the forefront of providing modem, acceptable and pioneering PD services. (Contact: 0118 956 1250 or www.winterbourne.demon.co.uk/news/ecellb.htm). Other internationally renowned units in this category are the Henderson and Cassel Hospital units.

Regional Psychotherapy Service Department, Newcastle upon Tyne: A specialist outpatient service for people with a personality disorder, offering psychoanalytically informed treatments leading to a reduction of self harming behaviour and the frequency and duration of hospital admissions. Patients become more skilled in managing emotions and relationships and improving the quality of their lives.
(Contact: 0191 232 5131.)

6.6 Services for People with Asperger’s Syndrome or High Functioning Autism (AS/HFA)

The Nature and Extent of the Issues

6.6.1 Autism is a complex developmental disability, of life-long duration, affecting the way in which an individual perceives his/her environment, behaves, communicates and interacts. Core features of the disorder are impairments in social interaction and social communication, with rigidity and repetition in thought processes, activities and behaviour.[101] The term ‘autistic spectrum disorders' (ASD) has been introduced to include the range of presentations from those who are severely affected with a co-morbid learning disability, to the intellectually able ie those with Asperger's Syndrome (AS) or High Functioning Autism (HFA). The latter are often used interchangeably, although increasingly Asperger's Syndrome is used as a short-hand reference for both.

6.6.2 The National Autistic Society [102] (NAS) estimated the prevalence of all autistic spectrum disorders to be 1 in 16 of total population, whilst the Medical Research Council [103] cites 1 in 166. Similarly, there are varying estimates of AS/HFA. Several studies [104, 105, 106] suggest that approximately 1 in 300 people will have 'able autism'. It has been found consistently that significantly more males than females are affected, with reported ratios averaging 4 to 1. [107, 108]

6.6.3 Epidemiological studies continue to support opinion that the majority of people with ASD, possibly more than 75%, are within the 'average' or 'above average' range of intellectual ability.[109] Therefore, most are well outside the remit of services that are commissioned to support those with a learning disability (generally accepted as IQ<70).

6.6.4 Presentation of symptoms may be more subtle than those displayed by individuals with significant intellectual impairment, but are often equally and, indeed, more disabling. As a result of less 'obvious' symptoms, many have been mis-diagnosed during childhood, adolescence and even in adulthood. It is reported that 46% of people with AS/HFA in England and Wales are not diagnosed until over 16 years of age. [110] With improving recognition and increasing expertise, it is evident that substantial numbers of adults with High Functioning Autism/Asperger's Syndrome are already in receipt of existing mainstream mental health services. Experienced mental health professionals generally feel ill-equipped to provide appropriate support and therapeutic intervention for patients/clients with the specific deficits that are characteristic of autism.

6.6.5 Priorities For Action[111] recognised for the first time that intellectually able adults with ASD are presenting to mental health services and require specialist provision to address their needs.

6.6.6 Studies of adults with confirmed diagnoses of Asperger's Syndrome or High Functioning Autism indicate a high level of associated mental health problems, particularly affective disorders, often with onset during adolescence.[112, 113, 114] It is estimated that 15%-20% suffer from significant anxiety disorders[115] and 37% from depression.[116] Frequently, clients present to services due to anxiety or depression that may then initiate further assessment and subsequent diagnosis of a pre-existing ASD. Recent evidence suggests that there is a 1 in 20 prevalence of co-morbid psychotic illness amongst able adults with ASD, frequently precipitated by extreme anxiety. In surveys conducted by Barnard et al,[110] 50% of parents whose son or daughter was not diagnosed until after the age of 30 reported that their child had experienced mental ill-health. Of these, 56% had suffered from, and been treated for depression. A further 11% suffered a 'nervous breakdown' requiring hospital admission, and 8% expressed suicidal ideation or had attempted suicide. It is reported that able adults with ASD fit the high risk 'suicide prone' category.[117, 118]

6.6.7 From the Down Lisburn Trust Pilot Project[119] (total population 180,000) over 16 months, a total of 36 adults with confirmed diagnoses have been identified, almost two thirds of whom were diagnosed after the age of 17. The majority (69%) were referred from, and already in receipt of, mainstream mental health services. Co-morbidity of autism and a mental illness is confirmed in 55% of those participating in the pilot project (N=29), although most experience an anxiety disorder to some degree. 84% reside in the family home, 13% live with their partner, and only 3% are living independently with support at present. Only 13% have full-time employment, 6% part-time work, 16% part-time voluntary work, 9% attend New Horizons, 34% attend College, Training Centre or University. 22% have no meaningful occupation. An additional 94 adolescents, aged 13 to 17, have a confirmed diagnosis of AS/HFA and will require access to adult services in the near future. Many have additional attentional and hyperactivity disorders.

6.6.8 Given the possible total prevalence of ASD, it is evident that many adults do not present for diagnosis and may not require specialist professional assistance, but the extent of need is inevitably difficult to ascertain in the absence of autism specific services and appropriate information systems. For those who do seek help, the following service components are recommended as representing a minimum standard of provision by the NAS.[120]

6.6.9 **Assessment and Diagnosis.** Currently, there is a lack of expertise in the assessment and diagnosis of people with AS/HFA throughout Northern Ireland.

Clinics which specialise in this work are uncommon, not only in a regional context, but nationally and internationally. One local Community Trust has established a diagnostic service, specifically for intellectually able individuals who are referred with a query of ASD. Many adults coming to the attention of services have complex difficulties, often including co-morbid mental illness. It is essential that a comprehensive diagnostic evaluation is undertaken by professionals with expertise in autism and mental illness.

6.6.10 **Support.** Post-diagnostic support is extremely limited in Northern Ireland for all who have ASD, their families or carers. However, people with diagnoses of both autism and a significant degree of intellectual impairment are likely to fare somewhat better than those intellectually able individuals with autism, as the former are 'eligible' for provision by learning disability programmes of care. At present, appropriate support is almost non-existent for adults with AS/HFA as they are usually excluded from learning disability (by virtue of their higher cognitive ability) and from mental health services unless a mental illness is confirmed. Lack of appropriate services greatly increases the likelihood of secondary mental health problems developing.

6.6.11 Some individuals have been accepted by services for people with a learning disability, as providers currently have nothing else to offer. Whilst this is clearly inappropriate for adults with AS/HFA, and draws on already scarce resources, in most areas of Northern Ireland it may be the only help available. These professionals with expertise in learning disability, like their colleagues in mental health, do not feel that they have sufficient knowledge of AS/HFA, the therapeutic skills required, nor an awareness of the types of services that may be needed.

6.6.12 To date, only one Health and Social Services Trust has developed a pilot project designed to assess the needs of individuals with AS/HFA and their carers, to support both, and to provide a therapeutic service specifically for this population. Some voluntary sector services have successfully provided sensitive individual support and accommodation.

6.7 Services for People with Disorders of Gender and Sexuality

The Nature and Extent of the Issues

6.7.1 The Psychosexual Service as a component of mental health services is uniquely positioned to address the emotional and bodily-based derivatives and expressions of disorders of gender and sexuality. The service must offer an expertise that addresses both sides of the mind/body equation within a psycho-physiological developmental framework. Although Northern Ireland has benefited from services located principally at the Belfast City Hospital since the mid 1960s, services throughout the United Kingdom are patchy. For example, in a recent survey[121] only 21% of commissioning authorities provide services at a local level for transpeople (individuals regarded diagnostically as transsexuals).

6.7.2 Psychosexual services provide for people with a diverse range of disorders of gender and non-organic disorders of sexuality. Rather than a spectrum of disorders, the diagnostic categories reflect quite different population groups with specific needs. For example, transpeople have a low prevalence (varying from 1/2900 for male to female and 1/8300 for female to male in Singapore[122] to 1/11900 for male to female and 1/30400 for female to male individuals in the Netherlands[123]) and constitute only 12-14 new referrals each year to the Northern Ireland Regional Service. However, due to the complexity and longevity of their needs, they often require significantly more input from services (on average treatment and follow-up lasting for 5-6 years) compared to individuals with, for instance, sexual dysfunction. Evidence suggests that transpeople demonstrate high levels of mental ill-health (requiring active psychiatric intervention) at the point of accessing services, often with high rates of parasuicidal behaviour and substance misuse,[124] and it seems likely that this is a direct consequence of difficulties with their sexual identity. There is also convincing evidence to support treatment of transpeople,[125] and that regret after sex reassignment is low, ranging from none to 3.8%.[126]

6.7.3 Although individuals with non-organically based sexual disorders constitute most referrals to psychosexual medicine (78% of referrals to the Belfast City Hospital Service) they tend to require shorter and less intensive interventions. This group of disorders appears to be very common throughout the general population, although precise data for Northern Ireland is as yet unavailable. However, studies elsewhere suggest prevalence rates for women may be as high as 43%[127] (a substantial number of which would require the assistance of a psychosexual service), with disorders of female sexual arousal constitute 70%[128] of attendances at psychosexual services. For men, erectile disorders have an incidence of between 7-25%,[129, 130] and 59%[131] have a psychological basis.

6.7.4 Individuals with disorders of sexual preference (paraphilias) constitute the other main category of referral (14% of referrals to the Belfast City Hospital Service).

There are few reliable sources of data in terms of incidence in the general population. Offenders tend to be dealt with through forensic and probation services. However, those who are referred to psychosexual services tend to have complex needs and may require specialist psychotherapeutic involvement over prolonged periods.

Current Services

6.7.5 The Psychosexual Service based at the Department of Psychiatry in the Belfast City Hospital has offered services on a regional level from the mid 1960's. In the 1980's the Western Health and Social Services Board developed a local, consultant-led service in Omagh. Some services for sexual dysfunction are also offered through family planning clinics, by a variety of mental health professionals with an interest in this area. In the voluntary service, similar treatment is available mainly through RELATE.

6.7.6 The largest and most comprehensive service remains that located at the Belfast City Hospital. The Psychosexual Team is led by a Consultant Psychiatrist and is constituted by multidisciplinary therapists including input from social work, nurse and general practice. Although there is access to inpatient places in Windsor House, this is only required on an exceptional basis and the vast majority of work is sessional and outpatient based. Most of the team members have accredited training in a range of psychotherapies.

6.7.7 In addition, through the General Practitioner Therapist there is a skilled focus on the assessment and treatment of certain physical aspects related to psychosexual disorder. Referrals are accepted from General Practitioners and Consultants in other branches of psychiatry, surgery and medicine. There are currently established links with services in Great Britain for the purpose of sex reassignment surgery (as this is not available in Northern Ireland), organised through private medical facilities.

APPENDIX 7

STATEMENT FROM EXPERTS BY EXPERIENCE

PREFACE

We choose to call ourselves Experts by Experience (EBE) rather than Service Users because the term highlights the unique contribution that we, who have direct experience of emotional distress and the mental health services, can make to the Review process and the development of mental health.

Given our distinctive expertise, the EBE Group felt it necessary to take a broader view than the strategy document and address some areas of fundamental concern, which were not explored within the Adult Mental Health Strategy document. The EBE Group identified the topics in this Appendix as central to the recovery process. We are the reason for existence of the mental health services and treatments, and we believe it was necessary for us to develop and publish our position on these issues.

LIST OF CONTENTS

MISSION STATEMENT

1.1 Everyone who lives has mental health needs. In an imperfect world people become emotionally stressed, depressed and unwell and they seek help and healing. Society's response in the western world is the psychiatric system which some of us have managed to survive with psychological scars and perhaps drug dependency but with a renewed sense of our rights to full citizenship, equality and self-determination.

1.2 We claim our rights to be valued for our dynamic diversity and dignity. As Experts by Experience we want to shape the environment, community and practice of mental health care, legislation and policy. A holistic approach is needed to acknowledge the reality of our emotional, spiritual, intellectual, social and physical being.

1.3 "Professional carers" who work in this field must be trustworthy and listen in an open, non-judgmental way, respecting our views and requests. This is essential to creating a partnership of trust, respect and empowerment.

DYNAMICS

2.1 We choose to call ourselves Experts by Experience (EBE) rather than service users because the term highlights the unique contribution that we as insiders can make to the review process and to the development of mental health.

2.2 The Experts by Experience group of the Review presents this paper because we want to assert that we are not just stakeholders responding piecemeal to the Strategic Framework, but central to the whole review.

2.3 We believe that the dynamics of the Review have been coloured by the fact that we were brought in at a late stage to validate or respond to agreements already in train. This may have reflected our previous status but now it is crucial to the Review that we have partnership, equality and power. We want full participation in a process that is transparent and person-centred throughout.

2.4 Although claims are made that the medical model of health, whereby a "patient" is deemed sick and needs treatment from an expert, has been superseded by newer models, our experience is that the attitude lives on in practice. This approach does not take into account the depth of the person's experience. Practice needs to be holistic and respectful of individual personalities and of social or spiritual aspirations and attainments.

2.5 Every aspect of human behaviour can be classified as a symptom. We want the mental health environment run on needs based criteria rather than being dependent upon divisive labels and symptoms.

2.6 We believe that we as experts hold a wealth of information about the roots of our distress and the process of recovery. Our autobiographical evidence must be given more importance than clinical data. Until our evidence and feedback is included, the quantifiable outcome is flawed and seriously undermined.

2.7 Every one has mental health needs and it is possible that anyone might at some time need mental health services. No one can dispute this. However the legacy of the medical model creates unacceptable divisions between the perceived sick and the healthy, normal and abnormal, good and bad.

2.8 Further divisions are made when labelling "severe and enduring", which in turn leads to unjust prioritisation of needs and services. Divisions also exist amongst professionals, which create unhelpful hierarchies resulting in some workers being undervalued and demoralised.

2.9 We want true partnership in our struggle to recovery, based on transparency and accountability, to a code of good practice that has the agreement of the Experts by Experience group.

PERSON-CENTRED APPROACH

3.1 Within our diverse Experts by Experience group, each of us has our own horror story of the effects of when we were controlled and felt as if we were being treated as objects rather than persons. There is consensus within the group that if only one element could be changed we would wish it to be the prevailing attitudes of those who engage with us.

3.2 The language of the Strategic Framework document is well seasoned with the words “person-centered” and whilst we acknowledge that this is well meant and a good step forward, without definition it loses significance.

3.3 Our definition derives from the Rogerian approach in that we want to be viewed as being at the center of our own universe, which has validity for us. We want to be understood as we are, with our dignity and unique story rather than in relation to preconceived and disempowering concepts. We have faith that everyone and not just users, has the capacity for and tendency towards fuller functioning and self-actualization, if these are nurtured by empathy, congruence and respect. We all have within ourselves vast resources for self-understanding and for being able to learn and change.

Congruence, Empathy and Unconditional Positive Regard.

3.4 As any number of users of mental health services can testify at great length,possession of these skills and the communication of them is not innate in service providers and carers. They have to be taught and learned.

3.5 Training in the person-centered approach is different to all other clinical approaches because it demands that the therapist wholly takes their lead from the client. It is rigorous and rewarding because it is process oriented and based on being rather than doing. It is a very difficult skill to master often depending upon holding back rather than imposing solutions

3.6 We need all professionals in the mental health field to have specific training in the person-centered approach as part of their overall learning.

3.7 At present the only therapy mentioned in the Strategic Framework document is Cognitive Behavioural Therapy. This may be a helpful therapy based on admirable theories but it is only part of the picture. As users of mental health services we want a broader choice of therapies and we want them delivered in a person-centered way.

3.8 Person-centred therapy training and provision is fairly widespread in the rest of the U.K. There are more person-centred training places on British Association for Counselling and Psychotherapy (BACP) accredited training courses than for any other therapeutic modality. An additional interesting statistic is that in terms of the major academic publishers, book sales in the person-centred therapy domain are greater than all of the other therapeutic approaches combined.

3.9 A similar, though not quite so pronounced bias is noted in terms of the employment of counsellors, particularly in the field of primary health care. For example the Lanarkshire Primary Care Trust employs a total of 16 full time therapeutic counsellors to work across 61 general medical practices. This contract is in its ninth year and it operates on a specification laid down by Lanarkshire Health Board which required the employment of person-centred therapeutic counsellors. The view taken was that the evidence for this approach was equal to others, including CBT but a notable factor was the distinct patient preference for the person-centred modality.

3.10 Exactly the same pattern of evidence is reflected in the largest randomised control trial into primary care counselling ever conducted in Britain. The King study found that found equivalence between person-centred therapy and CBT over four month follow-up, but again with clear patient preference for person-centred over CBT[2].

3.11 The consistent representation of CBT as having better evidential base over other approaches is seriously questioned in the latest edition of Bergin and Garfield's Handbook of Psychotherapy and Behaviour Change (Lambert, 2004). A particularly notable paper in this regard is that provided by Elliott, Greenberg and Lietaar[3].

References:

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RECOVERY

4.1 Recovery needs to be at the very top of the mental health agenda and accepted as an integral and central part of any proposed model of mental health care.

4.2 Taking ownership of the term, we define it from our experience rather than acquiescing to a definition that derives from theoretical sources popular amongst professional mental health workers.

4.3 The concept of recovery is very personal and subjective, as such it must be self-defined. For some it is a journey, with significant landmarks, rather than a destination. Others describe it in terms of:

peace of mind

happiness

accepting who I am

independent living

power to change things in my life

living life to the full

learning to accept the limitations of my relationships

coping with what is rather than what I want

coping with life's obstacles in my own way

I think therefore I am.

4.4 The concept of recovery and empowerment should replace the old notions of maintenance and rehabilitation. For many, rehabilitation is cold and mechanistic and often dehumanising. For some it is redolent of industrial therapy centres, which may still have a role, but do not suit the needs of all people with mental health difficulties.

4.5 Mental health workers and service providers need to be aware of the often negative and disempowering effects of institutionalisation. We need to avoid the creation of a mind-set of controlled conformity and subservient compliance, which has been prevalent in approaches to mental health service users encouraging a form of learned helplessness.

4.6 What is needed is a full and satisfying life as the individual sees it. A range of alternative therapies and life enhancing programmes need to be made available. Some have found benefit in supported employment centres but work needs to be continued to ensure that such centres operate at a high standard, putting service users at the heart of activities.

4.7 The mental health worker's role is to support and respectfully encourage the person in their own journey of recovery. These efforts need to be enhanced by the work of the advocate, in particular the peer advocate, who can aid communication, creating positive relationships of equality.

4.8 The community also has a role to play in recovery by providing safe havens and places of sanctuary in times of crisis as alternatives to acute hospital. Peers, family and friends may also be involved in facilitating recovery.

4.9 Those of us who have experienced recovery, having come through difficult and tortuous journeys, have exceptional authority and insight. This enables us to offer hope and encouragement to others who are still wrestling with their own pain. Having survived, we are a valuable asset to a society struggling with its own brokenness.

PEER ADVOCACY IN MENTAL HEALTH

5.1 The Strategic Framework document acknowledges partnership with service users in service planning and delivery as a fundamental principle in mental health care. We support service user involvement, not in a tokenistic fashion, but with real consideration of the positive contribution we can make to the mental health care services.

5.2 Our experience will be invaluable in the monitoring, quality control, development and delivery of services. One strong and proven route to service user involvement is through the peer advocacy movement which we heartily recommend as being of unique value to all service users and our allies in the mental health statutory and voluntary services.

> "Given that there are no other diagnoses for which laws are passed requiring that patients follow doctors' orders, the ramifications of mental illness encompass a great deal more than the illness itself."
>
> "The peer movement is predicated on the idea that there is a knowledge base of proven, experiential, indigenous wisdom that has come from struggling with the problems of mental illness in concrete ways." [1]

5.3 Peer advocacy challenges the discrimination and stigma attached to "mental illness". It is also a tool for empowerment by which to build, or re-build, well-being for people whose mental health condition has damaged self-esteem and confidence, induced a sense of worthlessness, interrupted careers and contributed to social isolation and poverty. This empowerment and its benefits are experienced by both the advocate and the client of peer advocacy service.

5.4 Peer advocacy involves having an accredited training, a Code of Practice - with confidentiality at its core - and regular supervision. It includes information and peer support in areas such as talking therapy, self-management of one's mental health condition, coping strategies, physical health promotion, general mental health education, anti-stigma support, information regarding medications, green therapy (e.g. doctor's prescription for visit to gym, swimming pool or relaxation) and other alternatives or complements to medication treatments. Peer advocacy services include information and signposting for welfare benefits, housing, access to mental health services and access to education and training.

5.5 Peer advocacy makes a special contribution to recovery from mental ill health by offering hope to the person seeking help. It can be inspirational: the client sees a peer now strong and able, a good role model.

5.6 There is added benefit in service user relating to service user: clients can trust and feel respected. There is no power difference in the relationship. It is often easier to talk to a peer advocate because there is real empathy in the struggle to overcome mental health problems. The client is empowered as peer advocacy challenges dependency and gives them significant control.

5.7 Peer advocacy is truly person-centred: the client is the focus of activity. There is no conflict of interest: the peer advocate will act only upon the wishes of the client. The peer advocate listens empathically and the client can, sometimes for the first time, put their thoughts about their condition into words.

5.8 Peer advocacy aims to promote accountability in the mental health services and to contribute to ongoing improvements in services. In addition, we believe that peer advocacy, through better communication, enables mental health workers to support their clients' involvement in their own recovery.

5.9 Pressures on professional mental health workers limit the amount of time they can spend listening to clients. The client, therefore, frequently doesn't get enough time to describe his/her concerns. This can cause severe additional distress. The peer advocate can dedicate more time which the client finds helpful. Professional mental health workers can benefit from peer advocacy as well as clients because the advocate is well placed to articulate the concerns of the client.

5.10 Supporters of peer advocacy in the mental health services are well aware of these benefits. Peer Advocacy needs more appreciation, rather than the present patchy acceptance or resistance from mental health workers. There is no need for anyone to feel threatened by the peer advocacy movement in terms of power or job demarcation or professionalism. It merits inclusion, promotion and a spirit of partnership, as it is a valuable independent extra resource.

5.11 Professional mental health workers cannot claim to advocate for their "patients" when there is a contradiction inherent in their roles.

5.12 Contributions from the "Experts by Experience" are invaluable where the client has misgivings about their treatment or diagnosis or where the client is being disrespected for example being referred to as their condition.

5.13 Those Health Trusts who have welcomed and monitored peer advocacy know the professionalism of this service in relation to the client and the mental health workers. Clients report less frequent return to hospital, more hope for recovery and less dependence on key workers. Significant numbers of clients choose to return to the peer advocacy service and encourage other service users to do so. It is clear to these Health Trusts that peer advocacy is not simply a complaints or a welfare rights service.

5.14 As there is some resistance to peer advocacy we recognise that there is practical educational work to be done by the peer advocacy movement and its allies in the mental health services.

5.15 There is powerful user-led and experiential evidence to support our claim that peer advocacy is vital to the development of an enlightened mental health service.

Recommendations

1. That the role of the peer advocate, as advocating continually on behalf of people with mental health difficulties, be recognised as an integral part of the service.

2. That peer advocacy be accepted in all Trusts and by all professional mental health workers. That it should be welcomed, supported, resourced and promoted as policy.

3. That a publicly funded user-led advocacy body be established to oversee policies, standards, supervision protocols and codes of practice.

References:

This section is informed by articles in "The Advocate" - Magazine of the UK Advocacy Network, UKAN, 14-18 West Bar Green, Sheffield, S1 2DA. Tel: 0114 2728171

1 Choice Advocacy and Case Management Services, New Rochelle, New York (http://www.choicenr.org)

IN TIMES OF CRISIS

6.1 The consultation document on the Strategic Framework freely admitted (para 4.20) that:

> "People with severe mental illness often experience crisis which may arise through illness relapse or through problems coping with the demands of their social and personal situation".

We strongly contend that difficult or intolerable social and personal situations are very often the cause of the perceived mental illness in the first instance and the "treatment" meted out in the psychiatric system is what makes their illness "severe and enduring". We want to ensure that the evidence of the person concerned is heard and respected rather than dismissed as irrelevant and lacking insight.

6.2 To avoid the mistake of mistreatment arising out of perpetuating labels we recommend that people be given the opportunity for the root causes of their distress to be addressed.

6.3 Those with severe mental illness have what is generally referred to as a "diagnosis". This is a label, which carries a huge weight of so-called "evidence-based" prejudice with it. It also precludes any real possibility of recovery and creates a mentality of negative self-fulfilling prophecy. What we want is a climate of positive optimism and shared determination to find ways of overcoming crises and working towards recovery.

6.4 The consultation document on the Strategic Framework acknowledged (para 4.20) that:

> "in many circumstances admissions are likely to have an underlying social rather than medical cause, the likelihood of being admitted being more strongly correlated with social rather than clinical factors."

We support this statement and suggest that the emotional crisis may be a healthy and rational response to very unacceptable life circumstances

6.5 The consultation document on the Strategic Framework also stated (para 4.20):

> "Present evidence suggests that the majority of inpatients are admitted to psychiatric hospitals as emergencies." At times of perceived crisis it is

important to discern who experiences it as an emergency; the so-called "sick" person or others who find it hard to accept and cope with their behaviour.

6.6 If the cause of the "crisis" is social and emotional, the response needs to address these issues appropriately rather than simply medicating the problem. Close scrutiny of these responses on the ground shows them to be not only inappropriate, but also fundamentally unhelpful and untherapeutic as well as being an "inefficient use of resources". (At a recent conference of mental health professionals, it was asserted that 75% of prescribed medication is never actually taken by the recipient). We contend that this is a poor use of economic resources as well as a challenge to the current psychiatric system.

6.7 Medical responses may be appropriate but often are degrading and dehumanising. Witness instances, not at all uncommon where the "distressed person" experiencing perhaps intolerable social circumstances is subjected to the very clear mistreatment of being forcibly arrested by armed police and uniformed ambulance personnel very often in full public view and driven to an acute hospital ward to be physically dragged along a corridor, held down by uniformed staff (predominately male) and injected with a chemical substance against their will. No treatment could be more degrading, traumatising and dehumanising. The Strategic Framework acknowledges that it is inappropriate and ineffective.

6.8 In a society which claims to be committed to respecting the human rights and dignity of all its citizens we ask for this practice to be abandoned and replaced with more humane and appropriate responses. People in emotional distress must be treated considerately and not like dangerous criminals, detained against their will without a fair hearing and legal representation. It would not be at all acceptable in law for even dangerous criminals to be subjected to enforced drugging. Yet this is allowed to go on daily in our psychiatric hospitals.

6.9 What is needed is respect, care, listening, understanding, gentleness, empathy and the provision of a safe and welcoming environment. Hospitals do not often provide these responses. We, as Experts by Experience, recommend that crisis response should wherever possible be provided in the presence of peer advocates or, if requested, by the person experiencing the "crisis" it should be undertaken by caring and enlightened mental health workers.

6.10 It is paramount that the person in crisis has a choice in the matter of the care received and that it is not a “treatment” imposed with little or no regard for civil rights and liberties and self-determination. Current legislation allows for serious abuses such as those cited already. The response needs to be genuinely person-centred, and to recognise the rights and dignity of all concerned. If there are conflicting interests between the distressed person and the "carers", the person's right to self-determination and equality of opportunity needs to be safeguarded. Sometimes there can be unhealthy “collusion” between carers and professionals leaving the person at the centre of the situation disempowered.

6.11 Mental health crises need responses, which are open, respectful and just, demonstrating accountability and transparency. Home or respite service responses should be the norm. Medication will most often not be appropriate. It is a medicalising of an emotional crisis. A 24 hour telephone service staffed by caring and experienced people (preferably Experts by Experience or trained lay volunteers) would be much more helpful and less intimidating than the typical present treatment. Crises properly handled can actually become opportunities for growth.

TRAINING AND WORKFORCE

7.1 The Experts by Experience group would like to highlight several important issues with regard to training. We feel very strongly that in order for the new vision to be truly inclusive of service users and hence achievable, that the values and principles expressed by this Review must be genuinely upheld and implemented.

7.2 We express disappointment that both self-management training programmes and pro-active service user development initiatives were totally overlooked. Therefore we have genuine concerns about the valuation of our input not only to this Review but also to the future development of the perceived new vision in general. As mental health service users, we have become accustomed to and hence are acutely aware of any denial of the expertise that we have to offer.

7.3 For the proposed partnership to work there must be acceptance of our future role and our expertise and experience of mental diversity, and experience of services provided, all of which give us that extra dimension over head-knowledge and work-related experience. Expertise gained through trial and error, pain and hardship, separation and incarceration has taught us a lot;

- about ourselves,
- about others: we have a deep appreciation of what is happening for other people when they are in distress,
- about service providers, both statutory and voluntary: we have an understanding of what works and what does not work – what is most personal is universal,
- about all other statutory and voluntary agencies: the majority of service users know through actual experience how problematic it can be to have to sort out anything in connection with Social Security, DSD, housing etc. especially just after a time in hospital or when feeling particularly unsettled.

Service user led initiatives provide a safe, confidential and supportive environment among people who are known and trusted and who can help explore relevant issues.

7.4 Whilst we too may have academic qualifications or work related experience these could never equal our skills, relevant to mental health, which accrued through having mental health problems.

7.5 The ultimate goals of all of us involved in mental health care/support, must be partnership rather than authority; empowerment rather than control; personal self recovery rather than an emphasis on being managed/maintained by others.[1] Service users will continue to break down any walls of division; some erected in the name of mental health professionalism, and will work towards genuine inclusiveness in this sphere.

7.6 For this Review to be sincerely committed to the ethos of the new vision, the workforce must be inclusive of all those involved in the process of creating its reality, including service users and carers, in a meaningful way.

7.7 Due to the monopoly, upheld by legislation, that psychiatry has enjoyed and exploited in the arena of mental health in Northern Ireland particularly, serious damage has been done, and still is occurring, due to oppressive practices. The negative impact of institutionalisation - loss of self-identity, loss of independence and traumatisation has resulted in a great number of, especially hospitalised, mental health service users needing to be re-empowered, at various levels. This re-empowerment involves regaining belief in themselves as persons first and foremost, becoming confident again in their own individual abilities and strengths and reclaiming personal responsibility.[2]

7.8 The Experts by Experience group unanimously endorses that all those involved in providing care/support should be adequately and appropriately trained and educated in order effectively to work in true partnership to achieve these goals. Until this vision is truly implemented and is seen to exist, with service users sitting alongside professionals in joint planning, training and education, the existing power imbalance will endure between services users and professionals. In multidisciplinary contexts current practices can be particularly demoralising and destructive for those grass-roots professionals who work in an environment lacking any support from within their own managerial structure. Professional judgements are frequently overruled by clinical judgements. Independent advocacy also in this climate has limited efficacy. The psychiatrist's word is deemed to be final.

7.9 Therefore, responsibility and accountability in ensuring that adequate and appropriate planning, training and education are accessible to all persons involved must be equally embraced by all.

Recommendations

1. The establishment of An Ethical Framework Strategy which is inclusive and applicable to all involved in providing care/ support to people with mental health problems

2. The establishment of a Service User Involvement Planning Group, in collaboration with DHSSPS and Health and Social Services Boards, adequately resourced and appropriately located.

3. Mental health service users' individual life skills be identified, acknowledged, supported, encouraged and incorporated within all aspects of mental health service provision and afforded opportunities for continual development either though service user/professional or jointly led training and education.

4. Service users must be given real opportunities to use and enhance their skills through meaningful involvement in the planning, delivery, evaluation and monitoring of the services.

5. Service users should be actively involved in the recruitment of all personnel seeking involvement at every level in mental health service provision.

6. In order to modernise existing services in Northern Ireland, posts must be created enabling past and present service users to be employed.

7. Peer advocates must also be actively involved in all the multi-disciplinary teams that operate within and outside psychiatric and hospital settings. This is to ensure that the ethical principles established are upheld with the right attitudes

8. Service user involvement must be incorporated within the continuous assessment process throughout the duration of all professional training including psychiatry. Service users must be involved from the beginning of all training courses, including planning, working, in equal partnership at all levels, to ensure that trainees uphold the core values and principles of the agreed ethical guidelines governing the mental heath framework.

9. Service users must be involved in the ongoing education of mental health professionals in order to safeguard maximum efficiency of human resources and good practice.

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2 Bodman R.,Davies R., Frankel N., Mintol L., Michell L., Pace C., Sayers R., Tibbs N., Tovey Z. and Unger E.(2003} Life's Labours Lost The Mental Health Foundation, London.

TREATMENTS

8.1 As users of mental health services all of us have felt at some point abused by the system of psychiatric “care”. Treatment is therefore a very important issue for us. Recovery can only be fully realized in a person centered holistic context not undermined by diagnoses and predicted outcomes, which dictate the perceived “needs” of the individual.

8.2 Our main concerns about a treatment-led mental health service are as follows. The vast majority of research into “mental illness” is supported and funded by pharmaceutical companies, which have an undeniable vested interest. The biological, medical and genetic paradigm therefore predominates within the area of mental health. There is an obvious bias here. Research into the environmental causes and solutions to mental and emotional distress are neglected and often ignored. Alternative and complimentary therapies are undervalued and often unavailable.

8.3 Our experience tells us that choice of medication is rarely if ever given. Negotiation and participation in medical treatments is never encouraged and rarely facilitated. Information on medication is usually provided in an inappropriate form (prescription leaflets) and at times is explicitly withheld. This situation leaves the service user feeling at best disempowered and at worst resentful.

8.4 The mental health professional argues that although medications used to treat mental ill-health have significant side effects, these are regarded as the lesser of two evils: “better to endure the side-effects than become a danger to self or others”. Risk of non-compliance becomes the main concern for the mental health professional with coercion and forced treatments taking precedence over therapeutic work. Side effects such as paralysis, involuntary movements, extreme constipation and weight gain with the possibility of heart and kidney failure (to name but a few) are regarded as acceptable to the administering services though often intolerable to the recipient. There is a lack of balance here between the risks posed from the side effects of medications against the risk of relapse. Many people who receive such prescriptions often dispose of their drugs rather than take them and suffer the side effects. This is a great waste of resources that could be better utilized in providing helpful alternatives.

8.5 Research continually provides evidence on the effectiveness of medications. If these medications are so effective why do so many individuals relapse while remaining on their recommended dose? We have learnt that much of the evidence demonstrating the reliability and validity of medications has been found to be manipulated or misused to support the medical model of mental illness. Our experiences in reporting hitherto unknown side effects have been continually ignored and have only been taken seriously many years after our first reports.

8.6 We therefore have the moral right to question all evidence on the reliability and validity of medications. We have the right to ask questions, criticise when necessary and to be taken seriously. We have the right to all information available on medications and to be part of the monitoring process of the effectiveness of any medications we agree to take. We have the right to refuse medications.

8.7 We want more independent research done on the best methods to reduce medication dosage and the safest ways to eventually become free from all medications prescribed for mental ill-health. This would enable people to make a genuine choice about the use of medication.

8.8 We demand more choice, e.g. therapies and activities that can replace medications. We want more research done on the therapeutic benefits of complementary and talking therapies.

8.9 We have witnessed and endured the over-prescription of medications to crippling and often dangerous levels. We believe it is time that an independent body monitors the prescribing of medications for mental ill health.

8.10 A mental health service that is medically driven will never have the capacity or understanding to facilitate the spiritual journey that is essential for individual recovery.

Reference

The British Psychological Society (2000), Understanding Mental illness. Recent advances in understanding mental illness and psychotic experiences, Leicester.

CONCERNS ABOUT ECT

9.1 We are concerned about the administration and safety of ECT. We abhor the abuse of consent, particularly when nominally voluntary patients refuse consent and then become subject to the threat of detention which is often enforced. This is known as “de facto” detention, whereby a person enters a psychiatric unit voluntarily but is then threatened with being “sectioned” if they attempt to leave the premises or do not comply with the treatment offered (ECT or drugs).

9.2 We are opposed to ECT ever being a first-line treatment. Most of the Experts by Experience Group proposed an outright ban on ECT. An alternative proposal was a moratorium. A minority felt it should be a choice for those who wished it. No one is willing to have it (again) themselves.

9.3 In our presentation of research data our aim is to include compelling user-led and user-approved research to highlight the depth of feeling and concern we hold concerning this issue.

The 2001 MIND Survey: Experts by Experience

9.4 It is striking that most medical research papers on ECT never include reports of the patient's experience of ECT. In March 2001 the respected British mental health organisation, MIND released a nationwide survey of people who had experienced ECT, the "Experts by Experience" [1]. One third of these had ECT in the last 5 years. MIND was appalled at the damage still being done by ECT. This survey did not deal with the issue of calibration of machines or competence in administration, but simply how survivors of this procedure felt:

- 84% of respondents suffered unwanted side effects including permanent short and long term memory loss, reported permanent loss of past memories of skills such as the ability to read, write, play music, or concentrate, as well as headaches, drowsiness and confusion
- 73% of respondents were not given any information about possible side effects
- ECT has a racist aspect; respondents from black and ethnic minority communities were more likely to be detained under the Mental Health Act and to have received ECT without consent
- 72% found ECT unhelpful, damaging or severely damaging in the long term.

- 66% would not agree to have ECT again
- Depression (53%)was the most common diagnosis among respondents
- Over half (52%) were unaware they could refuse this treatment
- Over 40% reported permanent loss of past memories
- 36% reported permanent difficulty in concentrating
- In the long term, 43% of recipients found it was unhelpful, damaging or severely damaging
- One third of recipients felt hopeful before having ECT, but 29% felt terrified and 22% that they were being punished
- Only 8% had the opportunity to consult an independent advocate before making a decision about ECT

9.5 Having noted these findings, the survey acknowledges that some people found ECT helpful and some found it so when antidepressants were not helping, or that ECT worked more quickly. We present the negative findings because they so seldom see the light of day, and if these results can apply to the percentages of people cited, they can happen to anyone.

9.6 The Royal College of Psychiatry itself acknowledges serious concerns with ECT. Since 1980 three audits have been commissioned on the subject of its use[2]. Each of these audits document gross incompetence in the administration of ECT revealing outmoded, improperly adjusted equipment, carelessness, ineptitude and inattentiveness despite new guidelines. One survivor said,

> "Twenty years on, three guidelines, three audits and half a million patients further on, the Royal College still can't ensure decent standards of care in all or even most ECT clinics."

9.7 There is an increase in the number of countries which have banned or are in process of banning ECT. In this country, case law and jurisprudence to ban ECT already exists under Articles 4, 5 and 6 of the European Convention on Human Rights.

9.8 ECT still forms a key treatment strategy in the treatment of some people here and its usage varies greatly from area to area and from one psychiatrist to another.

9.9 We have major concerns about the issue of consent. This can only be freely given if full information is offered about all of the effects of the procedure and with no hint of intimidation should treatment be refused. Only eight percent of respondents in the Mind survey had access to an independent advocate prior to their decision. 73 percent could not remember being given any information about possible side effects. Information about alternatives to ECT are rarely offered, according to the experience of peer advocates.

9.10 Choice is an issue here as there can be no possibility of informed choice when the treatment is presented either as "the last option", or that by not taking the treatment, the possibility is of lifelong depression. This is tantamount to coercion.

9.11 There are contradictions in the system about which treatments are considered safe and what is a considered risk. Statistics about detained people having ECT describe them as "requiring it" [3]

9.12 We bring a sharp focus to the issue of the ethical right to make such a decision or to take a risk for another person which can carry such dire consequences. A lack of transparency about the numbers of treatments given and their outcomes also impedes decision making. We are strongly of the opinion that the individual should be the one to choose how to treat their body and mind.

9.13 Calls for evidence-based research miss the point that we as Experts by Experience are actually the evidence. The safety of ECT is a huge concern to us. We are concerned about the potential for brain damage, depression from memory loss and other long-term injury and at worst death.

Safety -Research Findings

9.14 These ethical and experiential issues are placed first because the call is always for evidence-based research. We, as Experts by Experience, **are** the evidence in a very real sense. The safety of ECT is a huge matter of concern to us. Medical literature in the English language reported over 400 deaths from ECT in the period 1942-1997[4].

9.15 Last year , NICE (National Institute of Clinical Excellence) published new guidelines restricting the use of ECT to those people with severe rather than moderate symptoms [5]. While MIND, other mental health groups and most importantly users and survivors, welcomed these guidelines, the RCP appealed to NICE to drop the new restrictions. The potential for brain damage, death and other long-term injury has been studied, debated, and the results published by scientists. Rather than reinvent the wheel, we have include a brief literature survey by an ECT review team led by Auckland University Geriatrics and Neurology Professor Craig Anderson [6]. This work forms part of a current submission to the New Zealand government in their campaign to ban ECT. This material is cited because of the abbreviated nature of the paper and so that those who wish may discover some of the reasons ECT is beginning to be discontinued in some countries.

Patient Deaths and Suicide

9.16 Reasonable evidence now exists to support the fact that death may often be a side effect ECT, particularly in elderly patients. Contrary to claims, death from shock therapy is not, as suggested, 1 in 10,000 but closer to 1 in 200.

9.17 A study involving 1,494 patients found no difference in suicide rates between “treated” and non-shocked depressed patients [7]. A close examination of the literature does not support the commonly held belief that ECT exerts long-range protective effects against suicide.

9.18 Memory Loss always accompanies the ECT treated patient. Even the US Food and Drug Administration (FDA) have now declared that ECT may cause brain damage and permanent memory loss. Contrary to the claim made that "patients receiving shock treatment do not suffer long term damage to their memory" and that "only 1 in 200 patients have trouble with memory after shock treatment" one study showed that three years after shock treatment 50 percent of patients complained of poor memory[8]. In fact, the 1 in 200 figure was most probably an estimate.

9.19 A recent Spanish study discovered that depressive patients appear to suffer considerable cognitive dysfunction during maintenance treatment with Electroconvulsive therapy (M-ECT). Researchers maintained "Compared with controls, M-ECT patients showed alterations in verbal fluency, mental flexibility, working memory & visuomotor speed." [9]

Neurological Damage

9.20 We are also convinced that the common statement made, that "ECT does not cause brain damage," is nothing more that psychiatric propaganda of the worst kind. There are many noted experts in the fields of both psychiatry and neurology who have reported brain damage as a direct result of shock therapy. Indeed, some early literature on the subject indicated that brain damage was the source of the "improvement"

Depression

9.21 The idea promoted that ECT treatment is effective in eradicating depression is also very questionable. A study carried out as early as 1978 showed little if any difference at 12 and 26 weeks between patients who received ECT compared to those who received "fake ECT" [10]. A further study carried out in 1984 also showed little difference between shock treated and non-shock treated patients after four weeks. A six-month follow-up also showed no difference[11].

Safety Aspects of ECT

9.22 The philosophy put forward in psychiatry that shock treatment (ECT) is very safe is certainly disputed. A study of death rates showed 23-45 percent higher death rate for elderly patients at one, two and three years after ECT treatment compared to a control group of similarly aged people that received alternative psychiatric treatment[12].

9.23 ECT-enthusiast Dr Coffey and his associate Dr Figiel found that 10 out of 87 (that is 11 percent of) elderly patients getting ECT for depression remained delirious between ECT sessions for no discernible medical reason other than the ECT itself. They documented by brain MRI scans that 90 percent of these unfortunate patients had lesions in the basal ganglia areas of the brain, and 90 percent also had moderate to severe white matter lesions [13].

Patients

9.24 With the continued improvement of drug therapy, the use of ECT in younger patients requires close scrutiny. An article in the American Journal of Psychiatry[14] reported that a 15-year-old girl with schizophrenia received 200 ECTs in 1 year. A 16-year-old girl diagnosed with dementia praecox was treated with 15 unmodified ECTs in 3 days. The girl developed an organic brain syndrome over a period of 3 weeks. Five patients were reported to have ended the course of ECT prematurely because of side effects. These included a depressed teenager who underwent a switch to mania after five ECTs; two whose treatment was discontinued because of increasing agitation; one who showed marked confusion after two treatments; and an 18-year-old female patient with bipolar disorder who developed neuroleptic malignant syndrome following one ECT, after which the course was terminated.

Conclusions

9.25 Mental health treatment, as in any medical procedure, should be about healing. It is time that government policy moved to the elimination of electroconvulsive therapy as an unproven and inherently inhumane procedure.

9.26 Effective humane alternatives to these barbaric and outmoded treatments exist now and should be promoted. An urgent and comprehensive review of ECT is needed.

9.27 The 2003 study, Pharmacotherapy Following Electroconvulsive Therapy[15], (JAMA,14 March 2003), highlights the fact that ECT is a short-term solution to a long-term problem. Although Dr Harold Sackeim said in his opening paragraphs that ECT had a relapse rate of 50 percent or better, his own study showed a relapse rate of 84%- of those who responded to ECT in the first place. The group that received nortriptyline alone had a relapse rate of 60%, and the third group (nortriptyline and lithium) had a relapse rate of 39.1 %. Furthermore, of 290 people who completed ECT, 114 (40%) did not respond.

9.28 While it is often difficult to find information presenting a view differing from that of the psychiatric community, the statistical and anecdotal evidence has become overwhelmingly in favour of banning any form of shock treatment or electro convulsive therapy (ECT) as a preferred treatment. ECT is an invasive, inhuman and extremely degrading treatment, which, when given without a patient's consent, almost certainly breaches human rights. In the same way that we no longer perform prefrontal lobotomies, ECT should now be relegated to the archives of psychiatric medicine.

Recommendations

Considering this information, the Experts by Experience Group has major concerns about ECT, and recommends:

1. That ECT is banned. (A minority opinion favoured it being kept as a matter of choice.)

2. No individual should be given ECT against their will whether they are detained or not. The practice of threatening voluntary patients with de facto detention or full detention unless they consent to ECT must end.

3. Any individual for whom ECT is being considered must have access to an independent advocate of their choice, and be provided with full information about ECT, including all possible unwanted effects. This explanation must be provided in a format accessible to the person and must be agreed.

4. Living Wills, or Advance Directives, made when a person is well and giving instructions on their choice of therapy should they become unwell, must be respected as having full legal status. Copies to be lodged with a solicitor, family doctor or consultant by the person. This would protect people against enforced treatment.

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Acknowledgements:

to Paul Connolly of the Northern Ireland Mental Health Commission, Anna DeJonge from New Zealand, Robert G. Anderson P.D from Concerned Scientists Against ECT, Leonard Frank, Don Weitz, All Wales Users/Survivors Network for the ECT Switch It Off Booklet, MIND, and all the people who have shared with us their ECT experiences.

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GLOSSARY

Typical Antipsychotics

Older antipsychotic medication with a higher risk of causing involuntary movements or muscle stiffness. Examples include chlorpromazine, haloperidol, flupentixol

First Generation Antipsychotics

See typical antipsychotic

Atypical Antipsychotics

Newer antipsychotic medication with a much lower risk of causing involuntary movements or muscle stiffness. Examples include clozapine, olanzapine, risperidone and quetiapine

Positive Symptoms

A cluster of symptoms including delusions, hallucinations and disordered thinking that can occur at any time in people with schizophrenia but are more common in the acute phase of the illness.

Negative Symptoms

A cluster of symptoms including apathy, slowness and social withdrawal that can occur at any time in people with schizophrenia but are more common in people with long-term illness

Delusions

Unusual ideas or beliefs that are out of keeping with the person's cultural or social background.

Hallucinations

Disturbances of perception, for example hearing voices when none are about.

Extrapyramidal side effects

A cluster of symptoms that resemble some features of Parkinson's disease. For example, difficulty in initiating movement, slowness of movement, lack of facial expression and muscle stiffness.

Mood Stabiliser

Medicine given to try and prevent excessive mood swings. Examples include lithium, valproate or carbamazepine

Electro-convulsive Therapy (ECT)

A treatment where a small controlled current is passed through the brain with the purpose of causing a seizure

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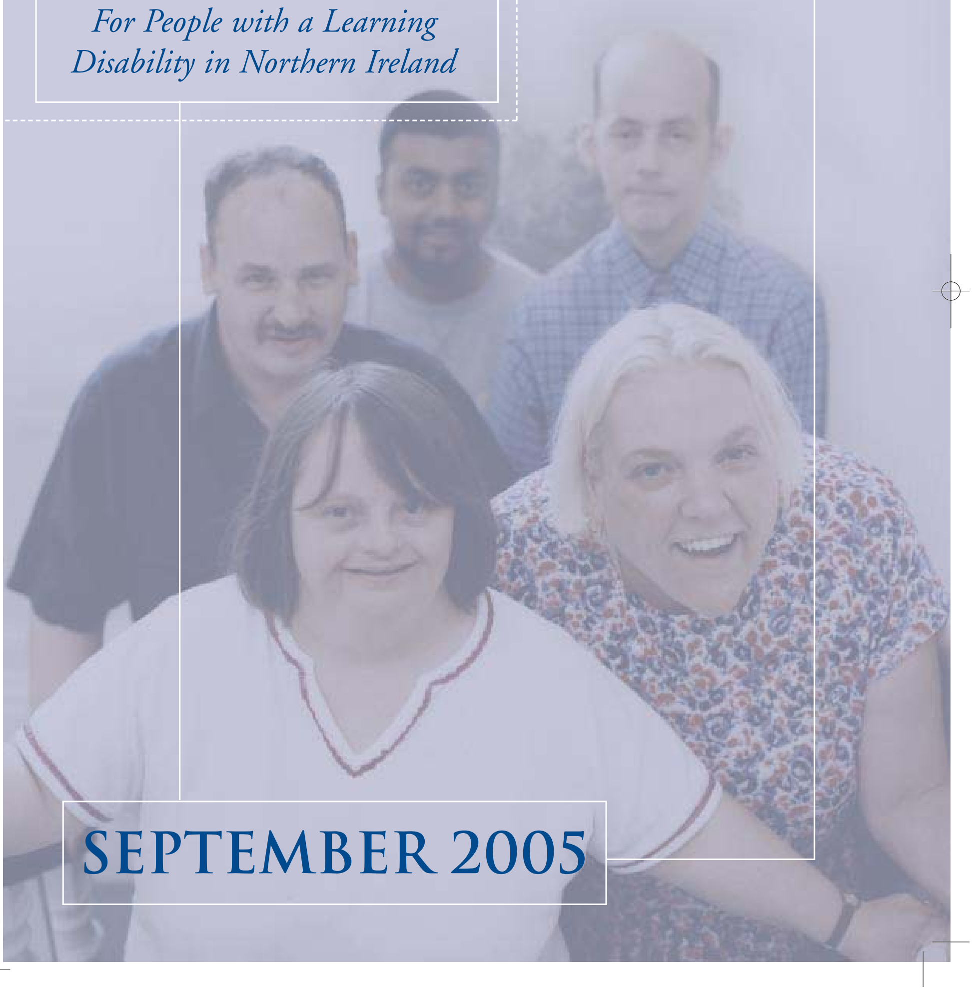
REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY

(NORTHERN IRELAND)

EQUAL LIVES:

Review of Policy and Services For People with a Learning Disability in Northern Ireland



SEPTEMBER 2005

EQUAL LIVES[1]

Explanation

Figures in bold in brackets refer to references to show where we got the information from. The details are given in Annex E at the back of the report.

Words that are underlined refer to words that are explained in the Glossary at Annex D.

The Glossary also lists all abbreviations that are used in this report.

Review of Mental Health and Learning Disability (NI)
Annexe 6, Castle Buildings
Stormont Estate
Upper Newtownards Road
Belfast. BT4 3PP
Telephone: 028 90 523480
E-mail: mentalhealth.reviewteam@dhsspsni.gov.uk
Photographs: Mencap
September 2005

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[1] During the Review we met every month with the Equal Lives Group; men and women with a learning disability who advised us on the work. They said that the Review should focus on ensuring that people with a learning disability have equal chances and choices to other people in Northern Ireland. We have called this report *Equal Lives* to reflect their priorities.

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PART ONE **WHERE ARE WE NOW?**

PART TWO **WHERE DO WE NEED TO BE?**

PART THREE **MAKING EQUAL LIVES A REALITY**

Annexes

FOREWORD

In the summer of 2002, I was invited to chair the independent Review of Mental Health and Learning Disability, commencing in October of that year. By March 2003 it was clear that the work consisted of several interlinked reviews under one overarching title, and encompassing policy, services and legislation.

The Review Steering Committee has presided over the work of 10 major Expert Working Committees. In consultation with Government, we agreed to produce our reports on a phased basis.

Equal Lives is the second report from the Review. It sets out a compelling vision for developing services for men, women and children with a learning disability for the next 15 to 20 years.

The Equal Lives Review has adopted an evidence-based approach, drawing upon existing relevant information and research, and where necessary commissioning research. Exemplars of best practice local, national and international, have informed the debate. Widespread consultations with stakeholders, in particular people with a learning disability and their families and carers, have endorsed our vision and the strategic direction of the Equal Lives Review.

The Equal Lives Review has concluded that progress needs to be accelerated on establishing a new service model, which draws a line under outdated notions of grouping people with a learning disability together and their segregation in services where they are required to lead separate lives from their neighbours. The model of the future needs to be based on integration, where people participate fully in the lives of their communities and are supported to individually access the full range of opportunities that are open to everyone else.

The success of implementing the Equal Lives recommendations depends on the contribution of many stakeholders, but most of all Government, who must give a lead on implementing the process of change. We fully recognise the resource implications and urge Government, in particular the Department of Health, Social Services and Public Safety, to begin the necessary process of reform and modernisation of these services immediately.

Professor Roy McClelland, deputy Chairman of the Review, and I thank Siobhan Bogues, who chaired the Learning Disability Working Committee, and all involved in the Equal Lives Review for their efforts and their commitment.

Professor David R Bamford
Chairman

Chapter 1

We hope the Review makes sure that people with a learning disability get the same chances and choices as everyone else. **Equal Lives Group**

Show us respect by giving us the support and information we need. **Family Carer**

About the Review of Mental Health and Learning Disability (Northern Ireland)

1.1 In October 2002 the Department of Health, Social Services and Public Safety (DHSSPS) commissioned an independent review of law, policy and service provision affecting people with mental health needs or learning disability in Northern Ireland. The Review of Mental Health and Learning Disability (Northern Ireland) could be described as having 3 distinct strands:

- a review of policy and service provision for people with a learning disability
- a review of policy and service provision for people with mental health problems
- a review of the Mental Health (Northern Ireland) Order 1986.

1.2 While there are overlaps between each of these strands there are clear distinctions and in particular, the Review of Mental Health and Learning Disability (the Review) recognises that learning disability and mental health problems are very distinct and separate conditions.

1.3 This is reflected in the way in which the Review is being carried out. An overall Steering Committee, whose terms of reference are shown at Annex B, manages the Review. They are guided by inputs from Expert Working Committees[2], each of which is examining a particular area:

- Adult Mental Health
- Child and Adolescent Mental Health
- Forensic Issues
- Mental Health Promotion
- Dementia and Mental Health Issues of Older People
- Social Justice and Citizenship
- Legal Issues
- Needs and Resources

The areas being covered by each Working Committee are given at Annex C.

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[2] Words that are underlined refer to items that are explained in the Glossary at Annex D at the back of the report

1.4 This report summarises the findings of the Learning Disability Working Committee and presents a wide range of proposals for improving the lives of people with a learning disability and their families by developing responses that are based on the key values of:

- Citizenship
- Social Inclusion
- Empowerment
- Working Together
- Individual Support.

1.5 The Review Steering Committee agreed the following Terms of Reference for the Equal Lives Review:

Terms of Reference

- To carry out a review of policy and services for children and adults with a learning disability
- To take into account the evidence base, national and international, for best practice in the assessment of need, the planning of supports, effective means of delivering services and the empowerment of people with a learning disability
- To comprehensively research the significant issues for consideration in future policy, utilising all reliable, valid and up-to-date evidence and to take account of local initiatives and needs
- To work collaboratively and consult widely with all relevant stakeholders both within and outside the health and personal social services sector
- To liaise as necessary with colleagues on the other Expert Working Committees on interface issues
- To bring forward to the Steering Committee a comprehensive and prioritised set of recommendations giving due consideration to cost, workforce issues and infrastructure needs.

How Did We Carry Out the Equal Lives Review?

1.6 The Equal Lives Review is based on an extensive range of consultations, research and analysis, carried out over the last year that included:

- establishing a Learning Disability Working Committee that managed the Equal Lives Review
- setting up the Equal Lives Group, which was made up of 16 men and women with a learning disability from different parts of Northern Ireland who met with us every month and gave advice on issues that they felt should be addressed
- meeting on 6 occasions with a group of family carers who gave feedback on ideas coming out of the Equal Lives Review
- holding 6 public meetings with men and women with a learning disability who talked about what they thought needed to change to make their lives better. Their views were collected by Equal Lives Group members and published in a separate report called We Have a Dream... (1)
- holding 5 public meetings for carers in different parts of Northern Ireland to share their concerns and suggestions. The issues raised at these meetings were published in a separate report - Focus on Families. (2)
- meetings with a group of young people who told us about the specific things they want us to address
- consultation with men and women who have complex health needs and/or a profound learning disability and their carers. The issues raised at these meetings were published in a separate report called Challenges of Complexity. (3)[3]
- setting up 6 Task Groups with various stakeholders to examine issues identified by the Committee as being particularly significant in relation to improving the lives of people with a learning disability - refer to Annex F for membership of the Equal Lives Review groups:
    - Support for Children and Young People and Their Families
    - Accommodation and Support
    - Day Opportunities
    - Ageing
    - Mental Health
    - Physical Health
- setting up a free phone line to provide an opportunity for people to share their views in a confidential manner. This service was designed for those who could not, or were unwilling to, attend meetings and to ensure that people from all over Northern Ireland could have their voices heard.

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[3] These reports are available on the review web-site www.rmhldni.gov.uk

- inviting people to make presentations to the Learning Disability Working Committee and Task Groups. Men and women with a learning disability, family carers and staff from a wide range of agencies all took this opportunity to tell us what is working well and what needs to change.
- inviting individuals and organisations to provide written comments. Many people took this opportunity to express their concerns and ideas to the Learning Disability Working Committee.
- holding conferences and seminars on particular issues attended by over 400 people so that new developments in services nationally and internationally could be presented and recommendations for local services identified:
  - day opportunities
  - lessons from Sweden
  - physical and mental health
  - lessons from other reviews on implementation
  - staffing and workforce issues
  - growing older
  - education
  - youth
  - family support
  - play
  - promoting equality
  - early intervention
- finding out what has happened in other countries and locally by reading policy documents and commissioning research from the University of Ulster. This research focused on 4 areas:
  - creation of a directory of research studies into learning disability undertaken in Northern Ireland[4]
  - strategic review of learning disability policy and service provision
  - reports on the 6 topics studied by the Task Groups
  - study of organisational arrangements and how they may develop in the future.
- 2 seminars for political representatives
- circulation of a consultation report to a wide range of individuals and organisations which resulted in over 70 written responses

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[4] This directory is stored on a cd-rom and is available free-of-charge from Room 12J10, School of Nursing, University of Ulster, Newtownabbey, Northern Ireland BT37 OQB

- an independent facilitator was commissioned to run a series of meetings with family carers and men and women with a learning disability to secure feedback on the draft Equal Lives report
- detailed consideration of all responses received and redrafting to produce this final report.

How Does Our Work Fit in With the Rest of the Review of Mental Health and Learning Disability?

1.7 The fact that the Equal Lives Review was conducted within a wider review of legislation, policy and services relating to mental health and learning disability had a number of advantages. First, it has meant that we have been able to inform the work of other Expert Working Committees, which will also address the mental health issues affecting people with a learning disability. Second, we have been able to liaise with the Expert Working Committees that are concerned with learning disability and mental health matters in equal measure, i.e. Legal Issues, Social Justice and Citizenship, and Needs and Resources. Third, we have been able to contribute to the current Department of Health, Social Services and Public Safety review of workforce in learning disability and mental health along with Review colleagues from other Committees. These Committees will produce separate reports, each of which will highlight issues and actions to be taken which should contribute to an overall improvement in the lives of men, women and children with a learning disability in Northern Ireland, albeit within the broader context addressed by that Committee. The Learning Disability Working Committee has highlighted the factors that we believe should be considered by these committees in their work. This report provides the overall context in which further recommendations from the various Working Committees will be placed. Their reports will be produced during 2005 to 2006.

1.8 However, we recognise that there are two main disadvantages of this approach. First, coupling learning disability with a mental health review may create confusion about the nature of mental ill health and learning disability, which are two very distinct conditions. In particular learning disability is usually present from birth, it is a life-long condition that cannot be cured and people with a learning disability require educational and social supports as well as health and social services. We would recommend that in future such an approach to addressing needs should be avoided.

1.9 Second, concern has been expressed about the fact that other committees are addressing some of the specialised areas of policy and service development that will affect people with a learning disability. This includes child and adolescent mental health, adult mental health services, services for offenders and the mental health needs of older people. The Review has sought to address this in a number of ways:

- the Steering Committee has met monthly throughout this process to provide an opportunity for an exchange between committees on developments and to formulate an overarching vision and strategic direction
- the Steering Committee gave a clear direction from the outset that all Expert Working Committees must address fully the needs of people with a learning disability as they relate to their particular area of focus
- members of the Learning Disability Working Committee have been members of the other committees where possible to ensure that overlapping issues are addressed
- the conveners of each of the separate Expert Working Committees have met regularly to identify and agree mechanisms for addressing concerns as to the interface issues

- members of the Expert Working Committees have been invited to participate in seminars and events across the Review to enable sharing of ideas and developments

- draft copies of the Equal Lives Review were shared with conveners of the other committees at various stages to facilitate a read across from this report to those that are being produced by the other committees.

1.10 We recognise that concern persists about separate areas of policy being addressed in different reports. In response to these concerns we have highlighted at relevant sections of this report the areas that we expect will be addressed in other reports. In addition the Learning Disability Working Committee will continue to meet throughout the life of the Review to consider emerging reports and offer guidance where necessary on the links between those reports and the Equal Lives Review.

How Do We See the Way Ahead?

1.11 People with a learning disability in Northern Ireland do not enjoy equality of opportunity and are often excluded from the opportunities that other citizens enjoy. Their families frequently suffer high levels of social disadvantage and their caring responsibilities can place them under almost unbearable levels of stress. There is evidence of progress having been made, but in order to fully tackle these difficulties there is a need for major co-ordinated developments in support and services and a continuing change in attitudes over at least the next 15 years.

1.12 We believe this will be best achieved through the adoption of a shared value base, a focus on shared core objectives and rigorous efforts across Government departments and agencies in the community to implement the change agenda that is detailed in the Equal Lives Review.

Equal Lives Values

1.13 The Equal Lives Review is based on 5 core values with which all policy and service developments must be underpinned. These values offer guidance for future developments and should be enacted for all people with a learning disability irrespective of age, gender, severity of disability or complexity of needs.

Citizenship **People with a learning disability are individuals first and foremost and each has a right to be treated as an equal citizen.**

Civil and human rights must be promoted and enforced. Government policy emphasises the importance of all citizens playing a role in civic society. People with a learning disability must be supported to be fully engaged in this agenda and their ability to exercise their rights and responsibilities needs to be strengthened. Citizenship recognises the unique contribution of each individual to their family and wider society and that the diverse strengths, needs and aspirations of people with a learning disability must be respected.

Social Inclusion **People with a learning disability are valued citizens and must be enabled to use mainstream services and be fully included in the life of the community.**

Inclusion recognises both people's need for individual support and the necessity to remove barriers to inclusion that create disadvantage and discrimination. Inclusion is only possible on the basis of equality of opportunity to access and to participate in education, employment, leisure and other aspects of community life. Inclusion is more likely to be achieved if people's connections are maintained at a local level through involvement in local schools, housing, employment, etc.

Empowerment

People with a learning disability must be enabled to actively participate in decisions affecting their lives.

Historically people with a learning disability have been excluded from decision-making processes and efforts must now be directed to affording opportunities to help them to learn how to participate effectively. They must be supported to have control, to have their voices heard, to make decisions about how they lead their lives and about the nature of support that they receive. Families and other carers need to be supported to enable people with a learning disability to take managed risks and lead more independent lives. It is recognised that some individuals with severe learning disability have particular difficulties with decision-making. For these individuals society needs to have robust arrangements in place to allow for substitute decision-making where required. The development of Mental Capacity legislation in Northern Ireland is ongoing through the Office of Law Reform and the Legal Issues Committee. We hope that this ensures transparent systems, based on promoting the human and civil rights of the individuals concerned.

Working Together

Conditions must be created where people with a learning disability, families and organisations work well together in order to meet the needs and aspirations of people with a learning disability.

People with a learning disability must be central to planning and decision-making processes. The role of family carers as partners in these processes should be recognised and valued. A wide range of Government departments and agencies in the community, voluntary, statutory and private sectors will need to work together to meet their responsibilities to people with a learning disability. Making change happen requires those with a responsibility for education, housing, health, employment, leisure and social services to be fully committed and involved.

Individual Support

People with a learning disability will be supported in ways that take account of their individual needs and help them to be as independent as possible.

Service systems that are based on group approaches need to be remodelled to more fully recognise people's individual strengths and needs. In particular people with a learning disability who have additional complex needs and their families may require highly individualised supports. Individual support will take a wide range of forms including staff, expertise, information and practical assistance. Individual support will also need to take account of the vulnerability of some people with a learning disability. Person centred planning will need to take account of this and ensure that appropriate risk assessments are completed as required. Where abuse or potential for abuse is identified, agency policies and procedures on the protection of vulnerable adults should be followed in the case of adults. Where the concern relates to children and young people the relevant sections of the Children (Northern Ireland) Order 1995 and associated multi agency child protection protocols should be followed. This approach will assist in managing the inevitable tension between the aspiration to accord full rights of citizenship to people with a learning disability and additional vulnerability that may be present as a consequence of the disability.

1.14 These values are a challenge to policy and practice, but are in keeping with recent legislative changes. The implications of these changes have not yet been fully realised in services, which traditionally have been based more on separation and dependency.

Equal Lives Objectives

1.15 We propose that future policy for improving the lives of people with a learning disability is directed toward attaining 12 core objectives over the next 15 years.

Objective 1	To ensure that families are supported to enjoy seeing their children develop in an environment that recognises and values their uniqueness as well as their contributions to society.
Objective 2	To ensure that children and young people with a learning disability get the best possible start in life and access opportunities that are available to others of their age.
Objective 3	To ensure that the move into adulthood for young people with a learning disability supports their access to equal opportunities for continuing education, employment and training and that they and their families receive continuity of support during the transition period.
Objective 4	To enable people with a learning disability to lead full and meaningful lives in their neighbourhoods, have access to a wide range of social, work and leisure opportunities and form and maintain friendships and relationships.
Objective 5	To ensure that all men and women with a learning disability have their home, in the community, the choice of whom they live with and that, where they live with their family, their carers receive the support they need.
Objective 6	To ensure that an extended range of housing options is developed for men and women with a learning disability.
Objective 7	To secure improvements in the mental and physical health of people with a learning disability through developing access to high quality health services that are as locally based as possible and responsive to the particular needs of people with a learning disability.
Objective 8	To ensure that men and women with a learning disability are supported to age well in their neighbourhoods.
Objective 9	To enable people with a learning disability to have as much control as possible over their lives through developing person centred approaches in all services and ensuring wider access to advocacy and Direct Payments.
Objective 10	To ensure that health and social care staff are confident and competent in working with people with a learning disability.
Objective 11	To ensure that staff in other settings develop their understanding and awareness of learning disability issues and the implications for their services.
Objective 12	To promote improved joint working across sectors and settings in order to ensure that the quality of life of people with a learning disability is improved and that the Equal Lives values and objectives are achieved.

Making Change Happen

1.16 Twenty-first century services will need to attune to a changed perception of what it means to have a learning disability. Many people with this disability are capable of doing more themselves. Their needs and aspirations cannot be met solely by health and social services - they need support from education, housing, leisure, employment agencies and others.

1.17 We recognise that achieving these objectives will require a major programme of work that will include:

- changes to how funding is allocated
- securing additional resources to achieve key outcomes
- closer interdepartmental and interagency working
- significant attention to developing and reconfiguring the workforce
- setting up robust arrangements for ensuring the implementation of recommendations
- commitment and effective leadership from key decision makers, planners and managers.

1.18 We will set out in the chapters that follow a series of concrete recommendations that should be implemented to support the achievement of the Equal Lives objectives. These recommendations fit together like a jigsaw and provide a coherent framework for guiding the delivery of the change programme.

Chapter 2

MESSAGES FROM PEOPLE WITH A LEARNING DISABILITY AND THEIR FAMILIES[5]

See Me, Hear Me

> *We hope the Review will make sure that there are more advocacy groups and more chances for people to speak out and be listened to. We do not think this happens enough and that is why things go wrong.* (1)

2.1 Throughout the Equal Lives Review we have listened carefully to the views of men, women and young people with a learning disability. Often we were told that they are not listened to or given a full chance to have their views heard by those who are making decisions about them. We heard a very strong message that change is needed to the way that decisions are taken and the approach taken to respond to people's needs, wishes and aspirations.

Chances and Choices

> *We want the same chances as everyone else. Why is this such a problem?*
> Equal Lives Group Member

2.2 Many people told us about the different activities in which they are involved, but a lot of difficulties were also highlighted when people with a learning disability tried to make use of the same opportunities as others. Problems described included:

- difficulties for children in using the play opportunities that their peers enjoy
- serious problems in getting out and about because of a lack of suitable transport locally
- many men and women described how lonely they feel especially at weekends and the evenings when they have nowhere to go
- bullying was a big problem for many of the people we talked to. Some told us how unsafe they feel in their own homes and others described how they had been subjected to regular verbal abuse because of their learning disability.

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[5] Fuller details of these messages are contained in the reports of 3 of the consultations carried out as part of the Equal Lives Review. These reports can all be obtained from the Review website www.rmhldni.gov.uk.

- some of the men and women we met were keen to work or do further training but a lot of barriers were put in their way, including lack of opportunities, the perceptions of employers that they would not be able to do the jobs and the negative impact on their social security and other benefits if they took up employment.

> *I am ready to work but doors are always closed in my face because I have epilepsy and a learning disability. People don't want to know. Employers can't be bothered to have people with a learning disability.* (1)

2.3 Many people who attended the public meetings described how important it was to them to have friends who were not family members or staff. Lack of information about personal relationships and restrictions placed on such relationships were highlighted at each meeting.

2.4 For those who had been successful in accessing a range of leisure or work opportunities the benefits were huge.

> *They gave my son a life - he goes to the local youth club and joins in a lot of clubs just like any teenager.* Mother

Getting the Right Support

2.5 The importance of staff attitudes and skills was a recurring theme in all the meetings. When staff displayed knowledge about disability and sensitivity in their approach it had a very positive effect on the lives of both people with a learning disability and family carers.

> *My life has been totally changed lately. I got a new social worker a few months ago and suddenly I am getting a lot more help in the house. I got my first break ever a couple of weeks ago.* Mother

2.6 Families were very appreciative of many of the services they received. Feedback from parents whose son or daughter had profound disabilities or complex needs stressed the value of the support they received.

> *Trustworthy, familiar staff make my daughter feel confident.* **Parent** (3)
>
> *Work with the professionals at the day centre has definitely increased his life expectancy and improved his quality of life.* **Parent** (3)

2.7 Although there were some conflicting views among carers as to the type of services they wanted, they frequently described their efforts to get the right support as a battle. We were told that parents were often worn out and very fearful about the future for their sons or daughters. The concrete steps that would make a difference to family carers included:

- easier access to information about the help available to them and how to access it
- flexible breaks from their caring role and emergency support especially outside of normal office hours in the event of a family crisis
- more support in the home
- better training for staff and staff approaches that are based on respecting the expertise of the family carer and their central position in the life of their son or daughter
- improved access to practical changes to the home environment and provision of practical aids
- immediate implementation of the right to a Carer's Assessment and more tangible responses to the needs identified in those assessments
- better access to Direct Payments that meet both their needs and the needs of their relative in order to give them greater control in the nature of support provided
- planning processes that embrace the expertise of family carers and most importantly that lead to action being taken in response.

> *The parents are getting older and tireder, the children are getting older and lonelier, the pile of public sector strategies, plans, reviews and academic studies is getting higher and higher, meanwhile plus ça change plus c'est la meme chose. There's an industry of officials and professionals out there, supposedly supporting our kids but fellow stressed-out parents and the man who invented Playstations have probably done more for my child than the lot of them put together. That makes me mad, and sad.* (4)

2.8 The Equal Lives Group report clarifies what they believe is important in relation to support from staff. They want staff who:

- listen well
- know what they are supposed to do
- understand what to do in an emergency
- know a lot about learning disability.

They also stressed the importance of staff not wrapping them up in cotton wool and listening and acting on what they (the man or woman with a learning disability) felt was important.

Challenges of Complexity

2.9 Family members who care for a relative with complex needs had some very particular concerns. The complex needs related to those with an Autistic Spectrum Disorder (ASD) and learning disability, those with severe learning and/or physical disability, those with complex health needs and those with challenging behaviours. For many of these parents real concerns were expressed that the move towards social inclusion will lead to an even greater marginalisation of their family members. They were anxious that the social inclusion and equality agendas might not be open to addressing their concerns or meeting the needs and aspirations of their family members. It was noted that full involvement in community life is limited by the few facilities that are accessible and the negative attitudes of members of the public.

People stare all the time. **Parent (3)**

Public and some professional attitudes need to change. **Parent (3)**

2.10 Parents involved in the Challenges of Complexity (3) consultation made a number of suggestions:

- appropriate financial assistance to meet their accommodation needs
- improvements to day care to enable more sensory based activities and a wider range of activities
- communication training for all staff
- financial assistance to enable families to purchase a suitable vehicle
- changes in attitudes from all people to ensure all those with a learning disability, including those with very complex needs, can enjoy a full and meaningful life in their community.

2.11 The powerful messages we received from people with a learning disability and family carers have made an immense contribution to all our work on producing this report. This process of consultation and participation should be echoed throughout the work that will be required to implement the Equal Lives Review recommendations.

SETTING THE SCENE

Chapter 3

Modern Thinking About Disability

> *Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services.* (5) **United Nations (UN)**

3.1 In order to provide a context for understanding the issues which impact upon the lives of people with a learning disability this chapter will address a number of broad themes viz:

- rights and the law
- policy changes
- defining and assessing learning disability
- prevalence of learning disability
- the impact of the troubles
- service provision and funding
- inequalities and human rights.

Rights and the Law

3.2 The quotation from the UN typifies the radical shift that has occurred over recent years in how society perceives people with a disability. This shift has been demonstrated by a growing recognition in legislation and social policy that people with a disability are people first and foremost. The previous focus on what people cannot do is being replaced by an emphasis on how the impact of their disability might be reduced through appropriate support and the removal of barriers to their full participation in society.

3.3 Developments in Northern Ireland legislation have reflected these trends. The Northern Ireland Act (1998) states that *a public authority shall, in carrying out its functions in Northern Ireland, have due regard to the need to promote equality of opportunity between persons with a disability and persons without.*

3.4 Further legal entitlements of people with a learning disability and carers have been set out in legislation, which is summarised in Annex G. Recent legislation largely serves two main purposes.

- First, it ensures that people with a disability have access to the same range of opportunities as their age peers and that they are not discriminated against.

- Second, it should provide people with a disability with the additional services and supports they require to assist them to achieve a better quality of life and social inclusion.

The Legal Issues Working Committee

3.5 The Learning Disability Working Committee is aware of the current detailed work of the Legal Issues Working Committee, much of which impinges on the lives of many people with a learning disability. Issues such as guardianship, capacity and incapacity, compulsory admission for assessment and treatment, the Mental Health Review Tribunal, advocacy, legal representation, are all matters which clearly connect with this report. Issues around inheritance, eligibility to vote, to marry and to engage in sexual activities will also need to be considered, along with finding effective ways of helping people with a learning disability to exercise their rights. It is our view that the future legislation will need to address these issues fully. This may require 2 separate pieces of legislation - one of which would address issues of mental capacity and decision-making and the second of which would address the legal issues for people with severe mental illness, irrespective of whether or not they have a learning disability. Learning disability interests are represented on the Legal Issues Working Committee and continue to be regularly articulated there.

Policy Changes

3.6 Changes in societal perceptions of disability are also reflected in the policy aspirations that underpin much of current service planning and delivery. These changes are clearly seen in the recent reviews of learning disability services undertaken in these islands over the past 15 years.

- The 1990 review of services in the Republic of Ireland was based on a philosophy that every one with a learning disability has the right to *as fulfilling and normal a life as possible.* (6)

- The last review of policy for people with a learning disability in Northern Ireland that was conducted by the Department of Health and Social Services in 1995 stated that *the aim of Government policy for people with a learning disability should be inclusion ... which stresses citizenship, inclusion in society, inclusion in decision-making, participation so far as is practicable in mainstream education, employment and leisure, integration in living accommodation and the use of services and facilities, not least in the field of health and personal social services.* (7)

- The Scottish Review - The Same as You? (2000) (8) - and the English Review - Valuing People (2001) (9) - were underpinned by a commitment to social inclusion, enabling people with a learning disability to have more control over their lives and securing equality of opportunity in accessing services in local communities. In 2001 the National Assembly of Wales set out the principles underpinning their framework for services for people with a learning disability in Wales, which similarly reflected a concern to secure equality, citizenship and improved quality of life for people with a learning disability. (10)

3.7 Over recent years the 4 Health and Social Services Boards in Northern Ireland have issued policy statements to guide their commissioning of services, each of which has echoed similar themes namely:

- inclusion within society as a right and the use of <u>mainstream</u> community services

- support to individuals that will reduce the impact of the disability on their lives

- focus on individual needs and aspirations and hence the provision of choices

- empowerment of people with a learning disability to make decisions
- partnerships are required to make these a reality. (11, 12, 13, 14)

3.8 These changes are also echoed in policy changes in relation to education, social security, children and family issues. All have been underpinned by aspirations to tackle inequality and open access to the opportunities that are available to other citizens in Northern Ireland.

3.9 It should be noted, however, that much of the evidence presented to the Learning Disability Working Committee indicates that these aspirational statements have not fully been translated into practice. In particular the Review of Policy and Services for People With a Learning Disability (1995) (7) pointed the way towards many of the changes that we are again highlighting in this report. The failure to fully implement the recommendations of that review appears to stem from a combination of the following factors:

- insufficient resources to build up the community infrastructure including community based alternatives to hospitals required to deliver on the strategic intent
- the lack of robust implementation mechanisms to hold all Government departments and agencies to account for their actions in implementing the recommendations
- the continued perception that the needs of people with a learning disability can be met solely by health and social services
- an underdeveloped culture of involving people with a learning disability and family carers in determining the services available to them.

3.10 The challenge for the future will be to build on the direction of travel that has been established in these legislative and policy developments and to learn from lessons of previous reviews to ensure that these aspirations become a reality within the next 15 years.

Defining and Assessing Learning Disability

Terminology

3.11 We considered the terminology that should be used to describe this condition, which included consultation with the Equal Lives Group to hear their views on the most acceptable approach. We recognise that the term *learning disability* has potential for confusion with the broader and educationally focused term *learning difficulty*. We also recognise that there is no universally acceptable term that defines people who have such diverse characteristics. Of greater significance will be the degree to which in the future those with a responsibility to reduce the negative impact of the disability address people's unique individual talents, needs and aspirations. We have decided to accept at this stage the advice of the majority of Equal Lives Group members who expressed a preference, if a term must be used, for *learning disability*. This will no doubt be the subject of ongoing debate as society continues to respond to the aspirations of those most affected by the implications of the term.

3.12 Learning disability is not easy to define. However, we recognise that in order to ensure that people with a learning disability qualify for the individual supports, protection and services they require, some form of working definition is required. Annex H summarises the definitions used nationally and internationally. Many of these focus solely on an individual's impairments and social functioning. Having examined a range of definitions we have adopted the definition used in Valuing People (9) and recommend the adoption of this form of words in future policy developments i.e.

3.13 ***Learning disability includes the presence of a significantly reduced ability to understand new or complex information or to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood with a lasting effect on development.***

3.14 In keeping with the Equal Lives model it is essential that account must also be taken of the person's social circumstances and the supports they require when applying these definitions.

Perceptions of Disability

3.15 Historically, definitions of disability, professional practice, and service delivery to people with a learning disability have been based upon a Traditional (Medical) Model of disability which suggests that it is primarily the individual's impairments that render them incapable of participating fully within society, and does not give adequate attention to the barriers imposed by society that exclude disabled people from participation and inclusion. During the past two decades however, the Traditional (Medical) Model of disability has been challenged and criticised on a number of fronts.

3.16 This has resulted in the development of what has become known as the Social Model of disability, which places a greater focus, or emphasis, on wider aspects of people's lives, including access to education, employment, health care, transport and housing, and the disabling nature of the barriers people face, in trying to access normal living.

3.17 However, we recognise that people with a learning disability are not a homogenous group, and that the needs of individuals can vary considerably. Therefore, it is our view that all services, across all sectors, should aspire towards a holistic, or bio-psycho-social model, encapsulated by inclusive and person centred approaches. This model allows for the holistic view of an individual's needs, implied by the core values of the Equal Lives Review.

3.18 This model includes the following:

- focus on the person and not the disability
- focus and emphasis on environmental and societal barriers that exclude people with a learning disability from society
- acknowledgment of the need for informed medical diagnosis and health care support
- can be applied across the range of learning disability
- use of a common and acceptable language to all
- forging professional and agency togetherness rather than divisiveness
- challenging segregated service provision and paternalistic practice.

3.19 Within this model there are four basic dimensions in describing the disabilities experienced by the person with a learning disability. These are depicted in Figure 1.

Figure 1

Four Dimensions for Describing Disabilities

1. **Impairments** – the presence and absence of specific impairments are noted including illnesses, mental and emotional problems.
2. **Functional limitations** – especially in the areas of activities of daily living (including personal care).
3. **Social inclusion** – the extent to which the person has access to education, transport, employment, housing, recreation etc.
4. **The supports** - (physical and human) available to the person and those that are lacking but needed.

3.20 Assessment on all 4 dimensions gives a more complete picture of the person, their life-style and needs. Equally 4 different terms (or more) should be used to locate the person within subgroups such as: *a 20 year old man with Down's Syndrome who has a severe hearing impairment, with significantly low scores on a test of intellectual disability and who requires assistance with all personal care needs; living in a residential home with 30 other residents.*

Defining Learning Disability

Why Assess?

3.21 A person needs to be assessed to establish if they have a learning disability for different reasons:

- to determine if they are eligible for services specially provided for people with a learning disability
- to find out if they qualify for legal protection accorded to people with a learning disability
- to make an assessment of the particular help or support they require because of their disability.

3.22 The assessment of a person's eligibility to services needs to be reconceptualised. The person's needs for services can be multi-dimensional as noted earlier. No longer is it reasonable to think in terms of one service; rather people may avail of many different services. Thus assessments of eligibility for services are rarely done on a once-off basis.

3.23 However, people with a learning disability do not need to be specially assessed to determine their eligibility for services that are available to the wider population as long as they meet the same criteria as their fellow citizens. We anticipate that this truism will have growing significance in future years.

3.24 In order to determine a person's needs for specific services, including provision for protection, that arise from their learning disability, the essential requirement is to specify the person's needs and vulnerabilities rather than their disability per se. In the past a low IQ alone was used to categorise persons deemed to have similar needs, but this is now being considered in tandem with an assessment of social functioning and a crude approach based solely on IQ should have no place in modern service provision.

3.25 The onus is on the service to precisely define the criteria that make a person eligible for the special service. Each defined service needs to produce and publicise the criteria for admission, especially for those services where demand exceeds supply, such as the provision of respite (short-term) breaks or attendance at day centres. The assessment of the person then becomes one of whether or not they meet the criteria for entitlement. This recognises the reality that everyone with a learning disability does not require every service. It also means that as people's needs change over time, they may become eligible for services; hence re-assessments of needs are required.

3.26 We view assessment of learning disability as an interactive process in which the person and their family carers are fully engaged with professional staff. This will necessitate services specifying more precisely their aims and criteria for admission while developing suitable and transparent means of assessing an individual's needs. There are encouraging signs that this is starting to happen in services, but it requires sustained attention in the coming years.

3.27 It is vital to ensure that a separate assessment of the needs of carers is conducted.

3.28 Until such times as present laws change, it is likely that thorough and precise assessments of intelligence and adaptive functioning will be required to determine if a person has either a significant or severe mental impairment as defined in legislation. However, this requirement need not carry over into definitions regarding eligibility for service provision for the reasons noted earlier. We anticipate that the Review's Expert Working Committee on Legal Issues will make further recommendations on this issue.

How Many People with a Learning Disability are there in Northern Ireland?

Prevalence

3.29 We have experienced some difficulty in securing accurate information on the prevalence of learning disability owing to the way in which such information is gathered in Northern Ireland. However, a recent study based on information held by Health and Social Services Trusts estimated the numbers as shown in Table 1. (Data from the Republic of Ireland are provided as a comparison). (15)

Table 1: Prevalence Rates (per 1,000) (15)

Age Bands	Mild/Moderate	Severe/Profound	Total	Overall Prevalence	RoI Prevalence(16)
0-19	6432	1718	8150	16.30	7.69
	39.3%	10.5%	49.8%		
20-34	2504	1047	3551	10.16	9.59
	15.3%	6.4%	21.7%		
35-49	1489	949	2438	7.04	7.81
	9.1%	5.8%	14.9%		*(35-54 yrs)*
50+	1473	753	2226	4.54	3.62
	9.0%	4.6%	13.6%		*(55+ yrs)*
Totals	**11,898**	**4468**	**16,366**	9.71	7.35
	72.7%	27.3%	**100%**		

3.30 These data suggest that many more children in Northern Ireland are recorded as having a learning disability than in the Republic of Ireland. However, in the latter, the figures are based on children in receipt of, or requiring, special services. In Northern Ireland many of the children classed as *possibly having learning disability* in the Child Health System may not be making any demands on special services. The prevalence figures for people aged 20 years and over are broadly comparable. The decrease in numbers of people by age reflects the shorter life expectancy of this group in the past. However, this is changing due to medical advances.

3.31 There is a small, but growing population of people from minority ethnic communities in Northern Ireland. Data is not available from present data systems, although under Section 75 of the Northern Ireland Act (1998) it should be recorded as these individuals and their families may have particular needs that are not currently addressed.

3.32 Finally, these numbers represent people known to services at a particular point in time. It is possible that the actual numbers of people with a learning disability are higher and they may come close to the often quoted figure of 2% of the population having a learning disability. This is especially so when those with milder forms of impairments, but allied with poor social circumstances, are included.

3.33 This would indicate that there is an unrecognised population of people with a learning disability of approximately 16,000 people who are currently not known to services.

Future Indications of Population

3.34 All the indications are that there will be increased numbers of people with a learning disability in the next 15 years. (17) This results from:

- increasing life expectancy - it is now thought that most adults with a learning disability in developed nations who live beyond thirty are likely to survive into old age and experience the normal ageing process
- people with more complex health needs are living into adulthood due to advances in medical care
- more mothers giving birth later
- increased survival rates of at risk infants due to improved healthcare
- the bulge in the numbers of children with a learning disability born in the 1950s and 1960s is now working its way through into the 50 plus age group
- a higher birth rate among ethnic minorities along with an associated higher rate of learning disability in these populations could also result in increased numbers.

3.35 There are some trends that may result in decreasing numbers or degree of disability:

- better pre-natal care for all pregnant mothers including increasing availability of pre-natal screening for congenital and other abnormalities
- improved health care and early intervention for at risk infants leading to fewer becoming learning disabled
- the advent of gene therapy to correct or ameliorate congenital abnormalities.

3.36 Overall it is impossible to predict the impact of these opposing influences. In England, a presumed growth of 1% per year for the next 15 years was made of people with moderate to severe learning disabilities. This figure may need to be higher for Northern Ireland as we have had a higher birth rate until comparatively recently and limited access to terminations of pregnancies. Even so a 1% increase per annum in the present adult population of 8,200 would mean an adult population of 9,500 by 2019. A 1.5% increase per annum would result in 10,200 people. It might also be that numbers would continue to rise for a further 15 years, up to 2034 before deaths matched births.

3.37 However, it is likely that higher proportions of these individuals would have increased support needs due to old age or additional complex needs and the impact on resources required to meet their needs would be in excess of a 15% - 25% growth in service provision based solely on the number of service users.

3.38 These factors indicate the increased demands that will be placed on existing pressurised services and the need to significantly develop community services to meet increased need into the future.

3.39 There may be increasing numbers of people from ethnic minority communities if immigration increases in Northern Ireland as it has done in the Republic of Ireland and Great Britain.

Links with Social and Economic Deprivation

3.40 Internationally there is clear evidence for a link between higher prevalence rates of mild/moderate learning disability and poorer socio-economic status and unstable family backgrounds. (18) This link with a severe learning disability is less clear-cut, but more recent research internationally does suggest a link with socio-economic status. (19)

3.41 Research in Northern Ireland has identified a significant association between the indicators of socio-economic measures of deprivation and the prevalence of people with a learning disability recorded on service information systems irrespective of the severity of their disability. (20) This is based on a small area analysis of the characteristics of people living within each electoral ward (i.e. around 2,500 persons) as ascertained by the national census or other form of surveys using representative sampling.

3.42 In Northern Ireland the association is best captured by three indicators of deprivation, namely there tend to be more people with a learning disability in wards that have:

- higher proportions of people aged 16 to 74 with no educational qualifications
- higher proportions of children in households with job seekers allowances
- higher proportion of adults with a limiting, long-term illness.

3.43 However, families who have a member with a learning disability may be poorer for other reasons (refer to Chapter 4). Therefore, many people and families are disadvantaged not only because of the disability, but also because of social and economic deprivation.

The Impact of the Troubles

3.44 It is notable that in many of the studies done on the impact of the Troubles on individuals and families, people with a learning disability do not feature. In part their invisibility may result from their small numbers, but more likely it is because of the presumption that their disability negates them from being influenced by the same factors that afflict their non-disabled peers. Indeed this presumption may well explain why in the midst of a segregated educational system, the only schools attended by children from both communities over the past 20 years were mostly special schools. Likewise much of the service provision for men and women is non-denominational although the balance of attendees from one rather than another community can be determined by its geographical location. (21)

3.45 In common with other public institutions in Northern Ireland, special schools and services seem to have been silent about issues of division, conflict and sectarianism. (22) There appears to be limited engagement in any reconciliation initiatives.

3.46 The findings from studies undertaken with other populations in Northern Ireland are also likely to mirror the experiences of at least some people with a learning disability. These have been summarised in terms of impacts that are more frequently experienced and less visible, to those that are less frequently experienced but highly visible. (23) These include:

- the risk of straying into areas where they did not feel safe
- getting stopped and searched by security forces
- sectarian verbal abuse
- parents having to take extra security precautions to secure home or workplace
- knowing victims of punishment attacks
- young people pressurised to engage in sectarian activities
- involvement in paramilitary activity
- member of family killed.

3.47 The clinical experience of professionals suggests that people with a learning disability were recruited by paramilitaries and that some were subsequently involved in serious offences.

3.48 More generally though, family carers were reluctant for their family member with a learning disability to travel independently and opportunities for social, employment and educational activities across the community divides were severely restricted. There are indications from local research that this social isolation may be one of the most widespread and lasting legacies of the Troubles.

3.49 However, it is impossible to generalise about the overall impact that the Troubles have had on this client population as no systematic studies have been undertaken and even when these have been done for the wider population, the results are difficult to interpret given the presence of other confounding variables such as socio-economic deprivation and lack of contrast groups from outside Northern Ireland.

3.50 Possibly the more important lesson is for the future and to ensure that people with a learning disability and service staff are fully involved in all initiatives to promote greater understanding and respect for the 2 main cultural traditions in Northern Ireland.

Service Provision

3.51 There is no accurate record of all services provided under the learning disability programme of care either by a Health and Social Services Trust or by a subcontractor in the private or voluntary sector. Nor are there accurate records of the number of people availing of them.

3.52 However, it is very apparent that over the past 20 years in Northern Ireland there have been major changes in service provision and an expansion in the range of services on offer. In particular:

- the 3 hospitals for people with a learning disability have reduced considerably in size and are evolving from providing long-term residential care towards the provision of short-stay assessment and treatment services
- in some areas there has been a shift in the provision of children's services from a learning disability programme of care to the generic family and child care programme and child health
- there has been a major growth in the provision of residential homes and nursing homes for people with a learning disability by a range of independent sector providers. Latterly increasing numbers of people have their own homes with staff providing support as required.
- there has been an increase in the range and quality of child care places but data available does not allow us to identify the extent to which children with a learning disability have benefited
- a wider range of day centres is available along with vocational training and employment services provided largely by the voluntary sector
- the provision of education for children with a learning disability has become the responsibility of Education and Library Boards and increasing numbers of these students go on to attend Further Education (FE) Colleges
- the health aspect of Early Intervention is now led by paediatric services with support from learning disability specialists
- a network of personnel from different disciplines and therapies are providing services to people with a learning disability living alone, at home and in community residential facilities
- a variety of different services have evolved to provide support to families and hardly any child or teenager now lives away from a family
- there is a growing appreciation of the need to facilitate and provide increased access to mainstream health, social services and education for people with a learning disability.

3.53 The result is a greater diversity of services with a wide range of personnel employed in them, which has produced a complex web of services spanning all sectors and a wide range of settings. However, this complex web of service provision has created its own particular difficulties including:

- family carers complain that they are not given information about all the services and help that is available (24)
- families may have to work with various different specialists who may give conflicting advice. The concept of a named or key worker for the family is not well established. (25)
- there is likely duplication within and across services in terms of record keeping, assessments and staff roles
- the full range of services is not available as often, new services have been developed in an area at the instigation of particular individuals or as a result of special project based funding. This produces inequalities within and across areas, a pattern that has been referred to as being a postcode lottery for support.

3.54 The need for joined-up working across different Government departments, statutory agencies and other service partners is very evident in the field of learning disability. It has received scant attention in Northern Ireland, although it is being actively promoted in Great Britain.

3.55 In recent years, increasing attention is being given to creating more person centred approaches in service delivery. Latterly Person Centred Planning (PCP) has been promoted as producing more effective outcomes for people with a learning disability in new styles of community-based services. However, recent research has indicated that PCP on its own may be ineffective unless the cultures of organisations change radically to create a shift in the power relationships between staff and the people they are working with and changes are made in funding arrangements and staff training and supervision. (26, 27)

3.56 In subsequent chapters we will address these and other issues through a series of recommendations.

Funding

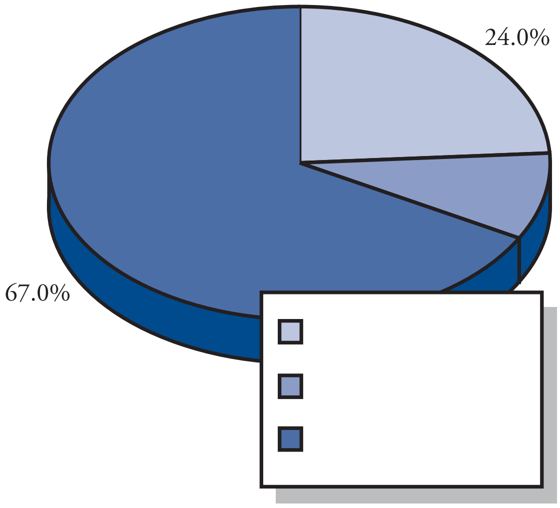
Health and Social Services Funding

3.57 The learning disability programme of care currently accounts for 7.6% of Health and Social Service Board expenditure (£136.4 million at 31 March 2003). This equates to approximately £80 per person of the total population. (28)

3.58 In the period 1997 to 2003 health and personal social services (HPSS) spending on the learning disability programme of care rose from £89.2 million to £136.4 million; an increase of 53%, although the later figure includes a substantial transfer of former social security payments to the HPSS. The share of the total HPSS spend also rose from 6.9% to 7.6%. (28) A detailed breakdown by key service area and by Health and Social Services Trust of the total learning disability expenditure for the latest available year (2002/2003) is given in Annex I.

3.59 The proportions of revenue monies spent in the HPSS learning disability programme of care as at 31st March 2003 are shown in Figure 2.

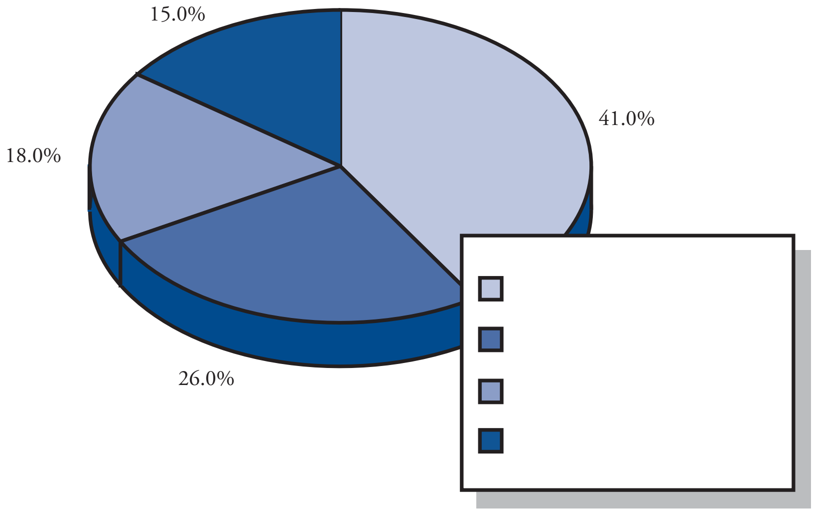
Figure 2: **The proportions of monies spent in the Learning Disability Programme of Care - year-end 31 March 2003 (Total £136.4 million) (28)**



3.60 There is a mismatch between the proportions of monies spent on hospital provision with the numbers of people in hospital settings (24% versus 4%). This can be explained to some extent in that the hospitals are funded to provide short-term assessment and treatment services for people in residential and family settings as well as for the people who live in hospitals. Total hospital expenditure has shown an increase of 9% over the 7-year period from 1997 - 2003. The overwhelming majority of hospital expenditure recorded for the learning disability programme of care is for inpatients with just over 1.5% relating to outpatients and 2% to day patients. However, all the costs of specialist medical and psychiatric services and some other services are presently costed to hospitals although they also serve people living in community settings.

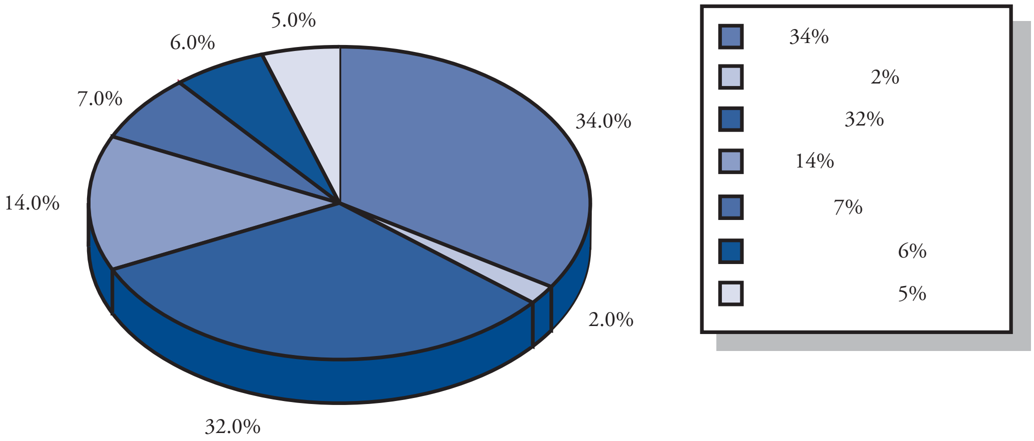
3.61 Community health expenditure has shown a 40% increase in the past 7 years, with the 2003 figure totalling £12.2 million (Figure 3). Expenditure on Allied Health Professionals includes speech and language therapy, physiotherapy, occupational therapy, etc as detailed at Annex D.

Figure 3: **Learning Disability Community Health Expenditure 2002/2003 (Total £12.2 million) (28)**



3.62 In personal social services (PSS) the largest items of expenditure recorded are residential homes/supported and other accommodation and day services as depicted in Figure 4. From 2002 onwards this received a major increase with the transfer of former social security payments to the HPSS. This was around £24 million but did not represent new monies, rather a reallocation of funds across Government departments.

Figure 4: Learning Disability PSS Expenditure 2002/2003 (Total £91.2 million) (28)



Funding From Other Sources

3.63 It has been difficult to obtain precise figures for the amount of monies spent by other Government departments on people with a learning disability. This will include:

- **Department of Education (DE):** on statutory assessments and statementing; the provision of learning support in mainstream schools and special schools
- **Department for Social Development (DSD):** social security benefits such as Disabled Living Allowance and Mobility Allowances plus contributions to Supporting People and the capital costs of special needs housing
- **Department for Employment and Learning (DEL):** further education costs, vocational training, Disablement Advisory Service and career guidance
- **European monies** have provided funding towards various learning disability services, although it is anticipated that these will end in 2006 or soon after.

Variation in Costs

3.64 To date there has been relatively little research into the costs of learning disability services and in particular into the value-for-money offered by different service models.

3.65 Most research in Great Britain has focused on different forms of residential care and found that costs vary dramatically within all forms of residential services. There can be a 4-fold difference in costs of these services and similarly a 3-fold difference has been reported for day services. (29) The level of dependency of the residents accounts for a proportion of the variation. However, once this is taken into account, there appears to be little association between the size of the home and costs. Larger is not necessarily more cost-effective.

3.66 Newer community based services are generally more expensive than support provided in older style accommodation, although this largely results from compensating for the inadequacies of these services rather than inherent economies of scale in larger establishments.

3.67 A Northern Ireland study into the costs of providing residential services for people relocated from a long-stay hospital found similar wide variation in costs as in Great Britain with the highest median costs being in registered residential care homes which cost £36,000 per annum (range £16,000 to £41,500) with costs generally lowest in registered nursing homes: median of £19,000 (range £11,000 to £36,000). (30)

3.68 Another study into the costs of supported living reported a wide variation in weekly costs, which were on average lower than figures cited for similar schemes in England, although some of these services employed waking night staff, which increases costs markedly. (31)

Inequalities and People with a Learning Disability

3.69 There is ample evidence to demonstrate that people with a learning disability do not have access to the same range of services and opportunities as other people in Northern Ireland.

3.70 The table, which follows, gives some examples of the inequalities that have been highlighted to the Equal Lives Review.

Table 2:	Inequalities Linked to Learning Disability
Children, Young People and their Families	Many children are unable to access mainstream play and leisure activities. (32)
	Access to preschool facilities for these children is curtailed.(33)
	Mothers are less likely to be in employment.(34)
	Mothers are more likely to report symptoms of ill-health such as depression. (35)
	The burden of caring is more likely to fall on the mother. (32, 36)
	Families of disabled children face financial burdens that are not always met by disability benefits and due to reduced income they are more likely to experience social deprivation. (37)
	Siblings of severely learning disabled children may also face inequalities with many having less contact with friends and increased levels of anxiety compared to other children. (38)
	Transition from school to adult services is a particular area of concern for parents. In the past commissioners and service providers have failed these children by not providing the same range of services and choices that are open to non-disabled young people, such as career guidance, further education, work experience and vocational training. (39)
Adult Life	People with a learning disability do not have the same opportunities in employment, further education, leisure, social life and personal relationships. Poverty contributes to some of these.
	Fewer people with a learning disability achieve accredited qualifications.
Health and Wellbeing	There are high levels of unmet health needs among people with a learning disability in Northern Ireland. (40, 41)
	Some may have a higher incidence of physical health problems. (41, 42)
	A person who displays challenging behaviours[6] is more likely to be socially isolated and excluded not only because of the behaviour they display, but also due to the barriers to their social interaction skills and development that challenging behaviours create. (43)
	Those with the most severe behavioural problems are also more likely to be excluded from day opportunities such as day care or school. (44)
	People who challenge services are frequently the last people to move out of institutional care (45) and the ones most likely to be admitted to hospitals for specialist assessment and treatment. (46, 47)

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[6] The term challenging behaviour as used here refers to people who challenge either due to behavioural causation (learned behaviour); mental health problems or both.

People who commit offences may not come before the courts but will have to live in more confined and highly supervised settings, often long-stay in hospitals. (48)

Growing Older

Many older people with a learning disability are at particular risk of neglect, poor access to health care and marginalization within society. (49, 50)

Some people with Down's Syndrome age prematurely and life longevity is reduced for many people with severe and profound disabilities. (49, 50)

Human Rights and Discriminatory Practices

3.71 People with disabilities may face more fundamental inequalities, foremost of which is the right to life. The European Convention for the Protection of Human Rights and Fundamental Freedoms is enshrined within the Human Rights Act (1998). At the centre of the human rights agenda is the fundamental principle that human beings have value and should be treated equally based on the fact that they are human beings first and foremost; human worth is not based on either capacity or incapacity. (51,52) These rights include the right to life, the right to liberty and security and the right to respect for a private and family life. These rights should never be restricted solely on the basis of the presence of a learning disability.

3.72 Questions do need to be asked however with regard to the inequalities that may exist in Northern Ireland detailed in Table 2. For example are statutory services in breach of the Disability Discrimination Act and Human Rights Act if they:

- fail to provide adequate community support for a person with challenging behaviours?
- exclude a person from day facilities or school because they do not have a nurse to care for his or her complex health needs?
- maintain a person in hospital because they do not have a facility in the community for a client to resettle to?
- deny access to health screening and treatment for a person by virtue of inaccessibility or exclusionary practice?
- do not have in place services to adequately meet the needs of older people with a learning disability?
- fail to provide family support, for example, respite?

3.73 Future legal challenges may test the legality of failure to provide adequate services in relation to the issues identified above.

Addressing Human Rights Issues

3.74 If institutionalised discrimination against people with a learning disability is evident in practice there remains an onus on Government and through them service commissioners and providers to address human rights and equality issues. It is our belief that in order to effectively address these issues services should be guided in future by the 5 values on which the Equal Lives Review is based: social inclusion, citizenship, empowerment, working together and provision of individual support. In addition efforts must be harnessed to change the attitudes and mind sets that support such discrimination and inequality. Various writers have noted that legislative implementation needs to be combined with:

- education of service staff who may discriminate against people with a learning disability
- moving forward the inclusion agenda by providing more integrated housing, education and day opportunities
- learning disability awareness raising through schools as evidence suggests negative attitudes are formed early in life, and when developed such attitudes are extremely difficult to change
- use of various local and mass media to raise the equality agenda for people with a learning disability
- raising awareness across agencies of the need to counter inequality
- raising awareness within associated services e.g. general hospitals, mental health services regarding countering inequality for people with a learning disability
- involving people with a learning disability in the design, delivery and management of services.

Possible Inequities in Service Provision

3.75 There are difficulties in comparing service provision between one area and another because of the limited information available, the lack of reliable research studies in this area and differences in the way services are provided. Despite this caution there do appear to be some marked differences in Northern Ireland service provision when compared with other countries e.g.:

- Northern Ireland has the highest proportion of people resident in long-stay hospitals:
  - 15 places per 1 million population in England and Wales (9)
  - 163 places per 1 million in Scotland (8)
  - 222 places per 1 million in Northern Ireland (15)
- There are many more places provided (or to be provided) in Northern Ireland hospitals for assessment and treatment admissions:
  - estimated 203 places presently available in Northern Ireland/ 11.9 per 100,000 population reducing to 146 (excluding forensic and children's places) (based on figures supplied by HSS Boards)
  - 3.98 per 100,000 population in Scotland (53)
- In Northern Ireland over one quarter of people with a learning disability surveyed lived in nursing homes. The proportion of nursing home places is higher here than in England and Wales, where in 1997 just 7% of their places were in nursing homes. However, the proportion of nursing home places varied within Northern Ireland; the Northern Health and Social Services Board (NHSSB) having the highest proportion (46%) and the Western Health and Social Services Board (WHSSB) the lowest (21%).

- The proportion of people in supported housing within Northern Ireland is lower than Great Britain, although there is wide variation across the four Boards; with the Eastern Health and Social Services Board (EHSSB) having the highest proportion (31%) and the Southern Health and Social Services Board (SHSSB) and WHSSB the lowest (4%).

- None of the Health and Social Services Trusts in Northern Ireland achieve the minimum number of funded accommodation places that the Department of Health has suggested for England and Wales, namely 15.5 places per 10,000. Again there is wide variation across the 11 community Health and Social Services Trusts from 6.8 places per 10,000 to 13.8 places per 10,000.

- More people with a learning disability attend day centres in Northern Ireland (23.5 per 10,000 of total population) than in Scotland (15.1 per 10,000) and England (12.0 per 10,000). (54) This may be viewed positively in that larger numbers of people have access to day centres and may redress the imbalance in the provision of residential places noted above. On the other hand, it could be that people in Northern Ireland have less access to further education, supported employment and ordinary leisure opportunities in comparison to people in Britain.

- In Great Britain not only do more people with a learning disability attend FE colleges (5.7% compared to 4.1% in Northern Ireland in 1999), but more are enrolled on a full-time basis (45% compared to 11%). (55) More recent figures supplied to the Equal Lives Review by the Department for Employment and Learning indicate that in 2002/03, 5.3% of all enrolments in FE colleges were for people with any form of learning difficulty or disability but this ranges from 1% to 13% across the 16 colleges in Northern Ireland.

- Although there are no centrally collated statistics in Northern Ireland, there appear to be more opportunities for people with a learning disability to be in supported employment in Great Britain and the Republic of Ireland. (16, 54, 56)

Future Prospects

3.76 It is important to end this chapter by highlighting the many positive achievements that have occurred within services for people with a learning disability in Northern Ireland over the past decade which have included:

- an increase of 53% in health and social services spending on people with a learning disability since 1997

- the increased resources provided by Education and Library Boards to special schools and units, and in support of children with statements of special educational needs in mainstream schools

- the increased number of children with a learning disability attending mainstream preschools, nursery and primary schools

- the increase in the number of Allied Health Professionals and other staff working with children and families

- the wider range of short-break options available to families and the reduced use of hospital provision to meet this need

- the reduction by 300 in the numbers of people living in long-stay hospitals since 1994

- the increase in expertise and support services that have enabled people with a learning disability and challenging behaviours to live in the community

- the increased diversity of accommodation and support options available to people with a learning disability and the numbers with tenancy agreements to their accommodation
- increased availability of further education, vocational training and employment options through European funding allied with Government funding
- the improved range and level of social security benefits available to people with a learning disability and their carers
- the wider range of innovative day opportunities that has been developed
- the greater acceptance by society of the rights of people with a learning disability and their willingness to include them in community life.

3.77 These improvements demonstrate that change is possible. They are also a reminder that the changes required in the future are but a continuation of what has largely begun. The foundations have been laid for the proposals for change that follow. It will be essential that data be collected to monitor these changes across all public services. This is already a requirement under Section 75 of the Northern Ireland Act 1998.

CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES

Chapter 4

> *The challenge to the Review is to get beyond the rhetoric and the research to recommendations that will get us closer to the vision of a world in which children with a learning disability will have equal choices and equal value.* **Children and Young People's Task Group.** (57)

Objective 1 To ensure that families are supported to enjoy seeing their children develop in an environment that recognises and values their uniqueness as well as their contributions to society

4.1 Recent trends in Government policy and legislation have emphasised the rights of children and the need to ensure equality of opportunity for all children. We have taken full account of the proposed children and young people's strategy for Northern Ireland and its welcome emphasis on including all children. However, frequently the particular needs of children and young people with a learning disability have tended to appear as a footnote in the initiatives that have emerged, but these are overshadowed by the numbers and needs of other groups. Children and young people with a learning disability have not benefited as they should from initiatives to improve children's experiences, or from measures focused on learning disability issues. We are proposing that there is an urgent need to address this situation in the firm belief that investment in children and young people is the most effective means of changing the experiences of people with a learning disability and their families.

Issues and Concerns

4.2 Many children and young people in Northern Ireland suffer from poverty and social disadvantage; these factors are increased where a family member has a learning disability. In Northern Ireland:

- 27% of the population is aged under 18 (58) making Northern Ireland the most youthful region in Europe yet we spend 25% less proportionately than England on children's services (59)
- 6.3% of children under 16 years live on family farms with an increased risk of isolation for all children and presenting serious challenges to families and services when a child has mobility problems (58)
- 29% of households are defined as poor with a further 12.1% vulnerable to poverty owing to low income. Half of these households include at least one member with long-term illness or disability (60)

- bullying is a significant cause for concern and unhappiness for children and young people with a learning disability. (61)

4.3 The views of children and young people with a learning disability are not routinely sought. When this is done it emerges that they share similar hopes and fears with their non-disabled peers, but also have additional specific concerns including difficulty having friendships, experience of bullying, isolation and barriers to play and leisure opportunities. (59, 62, 63)

Family Support

4.4 All children have the potential to bring to families great joy and equivalent levels of stress. Families are important to all of us, more so to the person with a learning disability. Families of people with a learning disability provide care and support well beyond what is normally expected and over a longer period of time. Families of children with a learning disability will at times report experiencing increased family harmony and cohesion, and higher levels of empathy among family members. For many other families however there can be preponderance of more negative experiences that drain the parent's or other main carer's ability to function as both an individual and as a long-term carer. (64)

4.5 The risk of experiencing such negative emotions is increased significantly for families:

- where the child has additional complex needs e.g.
  - children with multiple physical and sensory disabilities
  - children with an Autistic Spectrum Disorder
  - children who display high levels of challenging behaviours or mental health problems
  - families with more than one child with a significant disability
  - children whose disability is not easily identified and who don't look disabled
  - families where a parent has a learning disability
- at times of transition or change for the family e.g.
  - at the time of diagnosis
  - starting school
  - leaving school
  - transition to adulthood
  - leaving the family home. (65)

4.6 Children with a learning disability can display a range of special needs which require family members to fulfil a diverse range of roles and functions: parent, educator, communication facilitator, behavioural specialist, emotional confidant, advocate. Few carers could innately possess such a range of skills and, as such, need support and opportunity to acquire such skills. (66)

4.7 Positive developments in the support provided to parents over recent years include:

- increase in the number of Allied Health Professionals

- development in some areas of community based provision that facilitates access by children with a learning disability to community social and leisure opportunities
- the wider range of short-break options available to families and the reduced use of hospital provision to meet this need.

4.8 However, practical and emotional support to families tends to be fragmented and patchy. Although examples of good practice were presented to the Equal Lives Review, there was no evidence that such practice is consistent across Northern Ireland. Recurrent concerns presented to the Equal Lives Review included:

- Respite is currently defined as *placements, which are usually planned in advance, where a child moves out of the family home for a short break.* Provision is variable in Northern Ireland and parents frequently complained about their inability to access this provision particularly in emergencies.
- Provision of childcare has improved overall since the Government launched its most recent childcare strategy for Northern Ireland, Children First. (67, 68)
- The need for additional support for children with an Autistic Spectrum Disorder and/or multiple disabilities was highlighted to the Equal Lives Review.
- In addition there is an emerging need for additional provision after school and for older children.

4.9 Family support is not just about more services of whatever type being delivered to families in the hope that the cumulative effect will be helpful. Evidence has emerged in recent years both from outcome based research and families' own views that there are key elements of a Family Support model, which are crucial to successfully helping families cope. (65, 69)

Growing Areas of Need

4.10 There will be a number of growing areas of need over the next 15 years, which include:

- children who are technology dependant, an increasing number of whom are surviving into adulthood
- children with a learning disability who also have an Autistic Spectrum Disorder. Autism is a complex developmental disability of lifelong duration. The majority of those with an Autistic Spectrum Disorder do not have a learning disability and 75-90% are within the average or above average range of intellectual ability. (70) There is increasing evidence of the real life challenges experienced by these individuals who are often caught between learning disability, mental health and child health programmes of care. For those children with both an Autistic Spectrum Disorder and learning disability there is a need for appropriately skilled diagnosis and assessment and individual supports that take account of their particular needs. A ten year strategy to address the educational needs of children with Autistic Spectrum Disorders was detailed in the Task Force on Autism report. (71) Implementation of its recommendations requires close cooperation between the wider education sector and health and social services agencies.
- children with multiple severe and profound disabilities who require 24-hour personal care and increasingly intensive nursing care
- the numbers of children from minority ethnic communities are increasing

- increasing number of parents with a learning disability who may require additional supports to enable them to meet their parenting responsibilities. A survey in one Health and Social Services Trust found that 11% of families known to the children's disability team had 2 or more children with disabilities and for 5% of families one or both parents had a learning disability themselves.

- the nature of the family is changing. There are more lone parents caring for children with special needs. (72, 8)

Looked After Children

4.11 Children and young people grow and develop best in their natural families. Where the family can no longer provide the care or where the risks associated outweigh the benefits, this is not the case. Data are not available for all of Northern Ireland on the numbers of children with a learning disability who are looked after away from their natural families.

- A survey in the EHSSB found that 53 children with a learning disability were living in some form of residential accommodation (N=31) or with foster carers (N=22). (73) This represents 0.28 per 1,000-child population or 3.3% of children with a learning disability in the Board. If these figures were projected to Northern Ireland as a whole, this suggests that around 140 children live away from their natural families. Most of the children in residential accommodation were 14 years and over.

- In the Republic of Ireland, twice as many children (7%) live in some form of residential accommodation with an unknown number in foster care arrangements. (16)

- However, the study in the EHSSB area found that an additional 16 places were required to meet the needs of those young people presently living with families and that a further 14 places are also needed for those inappropriately residing in hospital or adult residential accommodation. If the figures for increased needs were projected to Northern Ireland as a whole, an additional 75 places are required for young people who need to live away from the family home in settings appropriate to their needs. Many of these young people have severely challenging behaviours and/or an Autistic Spectrum Disorder. They are difficult to foster because of their complex behavioural problems or health needs and they cannot be accommodated in mainstream children's homes. The lack of appropriate community provision results in some of these children being admitted to adult wards in learning disability hospitals and the lack of adequate provision makes it difficult to discharge them.

- Mainstream children's homes have difficulties supporting children with a learning disability, but where for an individual child it is appropriate that they do, staff require additional training and support to carry out this role.

- The lack of residential and foster placements is a recognised problem for all children. In a Social Services Inspectorate report in 2003, 95% of respondents reported a shortage. Social workers surveyed said that 17% of children with a disability always/nearly always did not have their needs met. Multiple care placements were identified as a serious challenge. (74)

Action Required

4.12 We propose that support to families with a child with a learning disability be remodelled to develop responses that are:

- more family directed
- continuously identify the needs and wishes of the family
- empower staff to support families in a more family directed, purposeful way
- able to direct resources flexibly.

4.13 In order to develop a more co-ordinated approach and to overcome many of the difficulties associated with families not knowing what support is available to them, a key worker should be appointed as soon as possible after diagnosis. This role has been recommended in other recent reports but as yet remains to be implemented in any consistent manner across Northern Ireland. It is imperative that a key worker be identified who will be linked with the family early and assume primary responsibility for co-ordinating service intervention and delivery. The key worker will be drawn from existing professionals such as social work, nursing or allied health professionals. The key worker will ensure that a Family Support Plan is agreed in partnership with the family that clarifies the support the child and family requires and how it will be delivered. The family and key worker should review the Family Support Plan annually. **(Recommendation 1)**

4.14 Respite services need to be developed in a manner that moves away from an over reliance on inflexible residential provision to the provision of a menu of short break services that include home based support, community based activity, family placements and residential options. The range of responses must take account of the intensive or specialist support needs of some children.

4.15 Children's Services Plans must detail how they will address the growing needs identified above with particular reference to deficiencies in short break provision, childcare and support in the home of families of children with Autistic Spectrum Disorders, complex health needs and/or multiple disabilities. **(Recommendation 2)**

4.16 It is vital that families have easily identifiable and accessible points of contact at different stages of their child's life. In the coming years, multi-agency centres should be developed to act as a focus for both generic and some specific services. These could be established from existing service sites, such as family centres, large primary care practices, community centres, nurseries or schools, but their existing remit would be widened through the addition of other information, support personnel and services. The goal would be to create a hub for supporting families so that help can be wrapped around the child and the family. This one-stop shop would also act as a common point of contact for children, their families and the staff who support them and would help to build clear referral pathways to further help and support and provide better co-ordinated responses. Children's Services Planning should be charged with developing this proposal in that such centres would be designed for all children in need and not just those with a learning disability. The evaluations of Children's Centres in England and the Wraparound Pilot in Northern Ireland provide models of service and evidence of the factors that contribute to success. (75, 76) **(Recommendation 3)**

4.17 As noted above we recommend that family support including planned breaks and emergency care in and away from home be prioritised in order to minimise family breakdown. To meet the needs for additional placements for looked after children specialist fostering and adoption should be further developed to ensure targeted recruitment of and enhanced support for foster and adoptive parents. Places for young people with a learning disability and complex needs aged 14 - 18 years who cannot be placed in a family situation should be provided in ordinary domestic settings and with regard to the principles of individual support, continuity and security of tenures of the supported living model. **(Recommendation 4)**

4.18 In order to address the complex and particular needs of children and young people with challenging behaviours and/or severe mental health problems community based assessment and treatment services need to be further developed. **(Recommendation 5)** The Child and Adolescent Mental Health Working Committee will make further recommendations in relation to children and young people with mental health problems. The interface between these services will be a key implementation issue.

4.19 Objective 1 Recommendations

Recommendation 1	Each Trust should have established arrangements for the development of Family Support Plans, which must be delivered through a co-ordinated strategy that monitors outcomes and identifies unmet needs.
Recommendation 2	Over the next 5 years providers should be resourced to extend the volume and range of emotional and practical help to support families. Their proposals should be considered within the context of Children's Services Planning and be aimed at assisting the maximum number of families. An ear-marked fund of up to £2 million recurrent each year for 5 years should be made available to fund proposals that best meet the Equal Lives values and objectives. The outcomes from this Family Support Fund should be carefully evaluated and used to inform future commissioning decisions in support of family carers.
Recommendation 3	Health and Social Services Trusts in partnership with Education and Library Boards and the community and voluntary sector should establish multi-agency centres, which provide a clear pathway to help for parents of children with a learning disability.
Recommendation 4	By March 2006 each Health and Social Services Board should identify the need for permanent placements for children and young people with a learning disability and produce strategies to address them. While the focus should be on innovative means of developing and supporting specialist fostering, it may be necessary to commission intensive care provision for small numbers of children who can not be placed in family settings.
Recommendation 5	Community based assessment and treatment services should be developed for children and young people with severe challenging behaviours and/or mental health problems. The service should encompass a small short-stay residential provision and community behavioural support services that provide outreach to families, schools and community based agencies.

Objective 2 To ensure that children and young people with a learning disability get the best possible start in life and access opportunities that are available to others of their age.

4.20 Energies need to focus increasingly on directly meeting the individual needs of babies and young children in a co-ordinated manner. As they grow older barriers to their inclusion in play and leisure opportunities enjoyed by their peers must be removed.

Issues and Concerns

Early Intervention

4.21 The value of early intervention with children with a learning disability has been well recognised, but the problems and challenges that exist are evident: (64, 68, 70, 77, 78)

- professional efforts are often not co-ordinated
- parents complain of having to manage multiple appointments and receiving at times conflicting advice
- long delays are reported for appointments to specialists
- key services are understaffed (79, 80)
- not all children with a learning disability receive a clear diagnosis despite the presence of complex needs. This can result in children losing out as service responses are often linked to diagnosis.
- families report that lengthy multiple assessments can often result in little direct therapeutic or education intervention
- parents also report great difficulties in accessing the information they need to fulfil their parenting responsibilities including information on support, benefits and their child's condition.

Play

4.22 To play is one of the fundamental rights as stated in Article 31 of the UN Convention on the Rights of the Child. There is an urgent need to address the invisibility of disabled children in almost all the forms of play provision. For many children with a learning disability current provision is still too often inaccessible, unwelcoming and fails to meet their needs. Attitudinal or logistical barriers often currently exclude children with severe and profound disabilities, an Autistic Spectrum Disorder, severe communication difficulties or challenging behaviours, from almost all forms of publicly funded play. (81)

4.23 Play provision using the child's home as the base can build the confidence of both child and parent to use the other forms of play provision. Toy Libraries, Sure Start and outreach from Child Development Clinics have the potential to enhance the quality of children's play at home. Home visiting services have demonstrated their value in promoting the importance of play to parents and developing parents' play skills in the early years. (82)

4.24 Policy and provision to promote play needs to take sufficient account of the very different role and form of play in the lives of children at different stages of their childhood. Many children with profound and multiple disabilities or complex health needs spend significant periods of time in hospital. Disabled children also spend time away from home using short break services and again the emphasis is all too often on care rather than play. All of these services used by children with a learning disability would benefit from more focus on play. (64)

Young People

4.25 Young people with a learning disability express the same aspirations as other young people to independence, work, learning, friends, marriage and a home.

- The experiences of young people with a learning disability are characterised by isolation and lack of social opportunities, creating over-reliance on families.
- Youth services identify the inclusion needs of young people with a learning disability as an equality issue but lack the resources to take forward the recommendations of pilot studies. (83)
- The vulnerability of these young people to mental and physical health problems, sexual exploitation and crime as both perpetrators and victims is well documented but little preventative or reparative work is done. (61)
- In learning disability services youth can get forgotten between children's and adult services. In mainstream services young people with a learning disability have difficulty getting heard. Young

people with complex needs are further excluded. There is a need for agencies to come together to address these issues across sectors and other administrative divides.

- Young people need to be supported to engage with the authorities to ensure their views are heard. The Interdepartmental Group that has been established by the Department of Education and Department of Health, Social Services and Public Safety to develop the range of support for children with special needs is an opportunity to ensure the broader agenda of young people's issues are addressed.

Action Required

4.26 In order to address the pressing need for information Health and Social Services Trusts should engage with partner agencies to develop accessible and timely information. This should be sensitively communicated to families at the point of diagnosis and at other major transition points. (78) There may be merit in exploring the feasibility of developing this at a regional level. **(Recommendation 6)**

4.27 In order to ensure that the needs of individual children are addressed in a more co-ordinated and effective manner the Family Support Plan should be complemented by the development, following diagnostic and assessment processes, of an agreed multi-agency Early Intervention Plan that is child centred. **(Recommendation 7)**

4.28 To address the current duplication and confusion about professional roles and boundaries and to support the development of key workers and effective Early Intervention Plans the Department of Health, Social Services and Public Safety and Department of Education should produce a comprehensive Early Intervention strategy that will:

- clarify pre-school years areas of responsibility between health and education
- consider how early intervention can be developed across all sectors including the training and research required in this area and also links within schooling
- review current provision models and resourcing
- extend and integrate the models of service that are currently being established for children with an Autistic Spectrum Disorder and which apply equally to children with other developmental disabilities. (71, 84, 85) **(Recommendation 8)**

4.29 The Department of Education and Department of Health, Social Services and Public Safety have a key role in ensuring equality of opportunity and addressing the needs of children with a learning disability. In order to achieve the objectives of the Equal Lives Review there will be a need for closer working and shared planning and funding where necessary. **(Recommendation 9)**

4.30 Children and younger people with a learning disability should have equal access to and benefit from play and leisure opportunities including sports and the arts. The Equal Lives Review has been encouraged to learn of initiatives in each of these areas that have included children and young people with a learning disability in community based play groups, after school clubs and youth services. However, there remains a lack of locally based accessible provision particularly for children and young people with profound and multiple disabilities. This needs to be addressed by ensuring that key agencies implement plans to reach children and young people with a learning disability. Public bodies should, therefore, require that the sports, leisure and recreational services for which they have responsibility evidence that they have been inclusive by monitoring uptake of their schemes and use of their facilities. **(Recommendation 10)**

4.31 In addition the Youth Service should mainstream the lessons learned from the pilot projects on inclusion and provide the support to ensure that young people with a learning disability get involved in decision-making processes in youth and other civic activities. **(Recommendation 11)**

4.32 Greater attention needs to be paid to addressing the increased vulnerability of children and young people with a learning disability to abuse and exploitation. The school curriculum for these pupils should encompass personal safety and personal relationship issues. **(Recommendation 12)**

4.33 The appointment of a Commissioner for Children and Young People in 2003 was a welcome development and the proposed children and young people's strategy should harness the efforts of a wide range of Government departments and other agencies towards achieving equality of opportunity for all children in Northern Ireland. The Commissioner could play a key role in ensuring that all agencies meet their inclusion objectives for children and young people with a learning disability. **(Recommendation 13)**

4.34 Objective 2	**Recommendations**
Recommendation 6	Each HSS Trust should set in place mechanisms to ensure that information on services and how to access them, benefits and support groups and other sources of help is automatically supplied to families at diagnosis/birth of their child.
Recommendation 7	Each HSS Trust should establish arrangements for the development of an Early Intervention Plan, which includes details of a key worker, for each child with a learning disability at his/her birth/diagnosis.
Recommendation 8	By June 2007 the Departments of Education and Health, Social Services and Public Safety should develop a regional strategy for early intervention.
Recommendation 9	By January 2007 joint planning and bidding mechanisms should be developed by the Departments of Education and Health, Social Services and Public Safety for services for children and young people with a learning disability.
Recommendation 10	The Department of Culture, Arts and Leisure, Arts Council, Sports Council, Education and Library Boards, Youth Council and District Councils should produce clear statements outlining how they are targeting provision for play, sports, arts and leisure opportunities for children and young people with a learning disability.
Recommendation 11	The Youth Service should mainstream the lessons learned from the pilot projects on inclusion and provide the support to ensure that young people with a learning disability get involved in decision-making processes in youth and other civic activities.
Recommendation 12	The Department of Education and Education and Library Boards should review the effectiveness of the programmes of learning for children and young people with special educational needs in relation to issues of personal safety and personal relationships. This should be supported with awareness programmes for parents and for others involved with children and young people.
Recommendation 13	The Commissioner for Children and Young People should be requested to monitor the effectiveness of all authorities in meeting their inclusion objectives. To facilitate this, the relevant departments should produce an Annual Report on the implementation of action plans.

FULLER LIVES

Chapter 5

> *I want my son to have a chance at education, to have friends, to get a job that he enjoys. Isn't that what you want for your children? Why should we be any different?*
> Mother

5.1 Ensuring that men and women with a learning disability are able to actively participate in their communities and afforded opportunities to meet their aspirations for meaningful day-time activities, friendships, employment, education and leisure was a key area of concern to all those who contributed to the Equal Lives Review. This chapter explores some of the issues highlighted and outlines a strategy for improvement that will require the active commitment of a range of Government departments and more effective working together between agencies, men and women with a learning disability and family members.

5.2 There is a pressing need to reform outdated policies and practices that are based on a belief that these issues should be addressed within the context of health and social services provision. An alternative model is required that challenges the social exclusion of men and women with a learning disability from mainstream services and proactively ensures their access to the same range of education, employment, personal relationships and leisure opportunities, whilst ensuring that individual support is available where required. Linkages with the revised anti-poverty strategy and actions are essential if we are to overcome social disadvantage and exclusion.

Objective 3	To ensure that the move into adulthood for young people with a learning disability supports their access to equal opportunities for continuing education, employment and training and that they and their families receive continuity of support during the transition period.
Objective 4	To enable people with a learning disability to lead full and meaningful lives in their neighbourhoods, have access to a wide range of social, work and leisure opportunities and form and maintain friendships and relationships.

Issues and concerns

5.3 The key issues may be summarised as relating to:

- the transition to adulthood
- supporting men and women with a learning disability who have complex needs

- further education
- day services
- employment
- transport
- leisure
- personal relationships.

Transitions

5.4 Education and Library Boards have key duties in planning for a young person's transition into adult life and are required under the Education Order (NI) 1996 to :

- inform Health and Social Services Trusts up to a year in advance of a young person with a statement of Special Educational Needs leaving school
- prepare a Transition Plan to allow for the coherent transition of the young person to adult life in partnership with parents and other agencies.

5.5 However, despite evidence of excellent practice including innovative initiatives in partnership with the voluntary sector, the experiences of many young people leaving school have been unsatisfactory.

- Various studies have documented the various difficulties that parents and young people have encountered during the transition years. (39, 63)
- Much of the planning occurs in the last year at school, which is too late to ensure that a range of options are sampled or explored.
- Careers advice is available to young people with a learning disability through the Careers Advisory Service. Input to individual schools varies but is better where good relationships have developed between the Careers Officers and the teachers.
- There is a striking contrast between the expectations of parents and young people and the lack of options that are available to them after school. (63)
- There are examples of good practice throughout Northern Ireland where partnerships between the voluntary and community sector and schools have resulted in positive outcomes, but there is no consistent access to such initiatives across Northern Ireland.

Complex Needs

5.6 There are a growing number of men, women and young people with a learning disability who have complex needs and multiple disabilities.

- Parents report that access to the services of Allied Health Professionals reduces upon leaving the special school.
- A growing number of young people who challenge services, some with a history of school exclusion.

- A few will commit offences and therefore come into contact with the criminal justice system.
- There are increased numbers of school leavers with a learning disability and an Autistic Spectrum Disorder.
- There is increasing evidence of dementia and Alzheimer's Disease amongst older men and women with a learning disability.

Further Education

5.7 There is scope for development of opportunities for men and women with a learning disability within Further Education (FE) in Northern Ireland.

- Significant variation exists across colleges in the number of students with a learning disability enrolled as a proportion of the student body ranging from 1% - 13% in 2002. (86)
- Average level of enrolments appears to be lower in Northern Ireland, 4.1% in 1999, as compared with 5.7% in England. (55)
- The number of students enrolled on full-time courses is also lower, 32% in 2002 in Northern Ireland (ranging from 10% to 67% across the Colleges) as compared with 45% in England in 1999. (Department for Employment and Learning and 55)
- Concerns exist about the lack of progression from FE provision; students not able to gain accredited awards from their study; the lack of links with job training and work experience; students repeating the same course content in subsequent years.
- It is encouraging that studies in Northern Ireland have highlighted a range of initiatives that are affording positive opportunities for young people with a learning disability to be involved in activities within the FE sector. This provision points the way towards the positive outcomes that might be achieved if such opportunities were more widespread and consistently available. (55, 87, 88)

Day Services

5.8 Traditionally the majority of school leavers from Severe Learning Disability (SLD) schools have been placed in day centres commissioned by health and social services agencies. The model of such provision has evolved over the years from an industrial/workshop philosophy to a social education model, which emphasises the development of social and life skills. More recently some centres are moving towards becoming resource centres where in-house attendance is combined with involvement in community activities. Concerns about the place of day centres in the service framework of the future led to the 4 Health and Social Services Boards to commission a wide-ranging review, the outcomes of which have informed the Equal Lives Review. (56) The main issues and concerns are:

- in 2002 an estimated 4,000 people were registered with day centres/training centres and workshops. This represents around 70% - 75% of men and women with a learning disability who live in their own accommodation or with family carers.
- 77 centres in Northern Ireland provide a service to men and women with a learning disability aged between 16 and 87 years. The profile of those using the centres includes people with

profound disabilities, those with an Autistic Spectrum Disorder, people with severe challenging behaviours and a growing number of individuals with dementia.

- demand for places exceeds supply. An estimated 180 children with severe and profound learning disabilities leave school each year. If all were to be accommodated in day centres an increase of around 20% in places would be required over the next 5 years with an additional cost of approximately £5.5 million.
- day centres have provided a valuable service to carers who have welcomed the respite for them and the opportunities provided for their son or daughter. However, they have also identified inadequacies including shorter opening hours, transport problems, and the need for more individualised planning.
- day centres can heighten the exclusion of men and women with a learning disability and reduce their engagement with the wider community.

Employment

5.9 Many men and women with a learning disability aspire to having a job and increasing numbers of parents share this aspiration for their teenage sons and daughters. The development of vocational training and the introduction of Supported Employment to Northern Ireland have opened up new possibilities for achieving these aspirations.

- Department for Employment and Learning's Disablement Advisory Service provides assistance to people with a disability to access employment. Programmes on offer include Access to Work, Employment Support, Job Introduction Scheme and New Deal for Disabled People. Mainstream programmes like Jobskills and Worktrack are also available. Significant numbers of young people with a learning disability enter the Jobskills Programme.

- Access to these programmes can be limited by factors such as admission criteria, outcomes required, duration of the programme and the pattern of provision.
- There has been considerable growth in Supported Employment in Northern Ireland over the last decade. The Northern Ireland Union of Supported Employment has over 15 non-statutory agencies in its membership and many other day centres are involved in this work. A number of other approaches to securing paid work have also developed including vocational training and social enterprises. Evaluations of such schemes have evidenced the benefits to individual participants although few of the trainees had made the transition to paid work. (89, 90). European monies from either the Building Sustainable Prosperity or Peace programmes have funded most of this provision. Urgent consideration needs to be given to mainstreaming the funding and the learning.
- A range of external factors impinge on the potential for men and women with a learning disability gaining employment including inflexible rules in relation to benefits, absence of clear intra-agency partnership, low expectations and a disparate reliance on health and social services funding. Difficulties in the reinstatement of benefits and the fact that wages earned may be lower than benefits received means that people may be reluctant to seek paid employment. This was seen as a major barrier to people with a learning disability accessing employment.
- The Department for Social Development has a role in clarifying what currently exists and considering how to make realistic alternatives to benefits work for people with a learning disability.

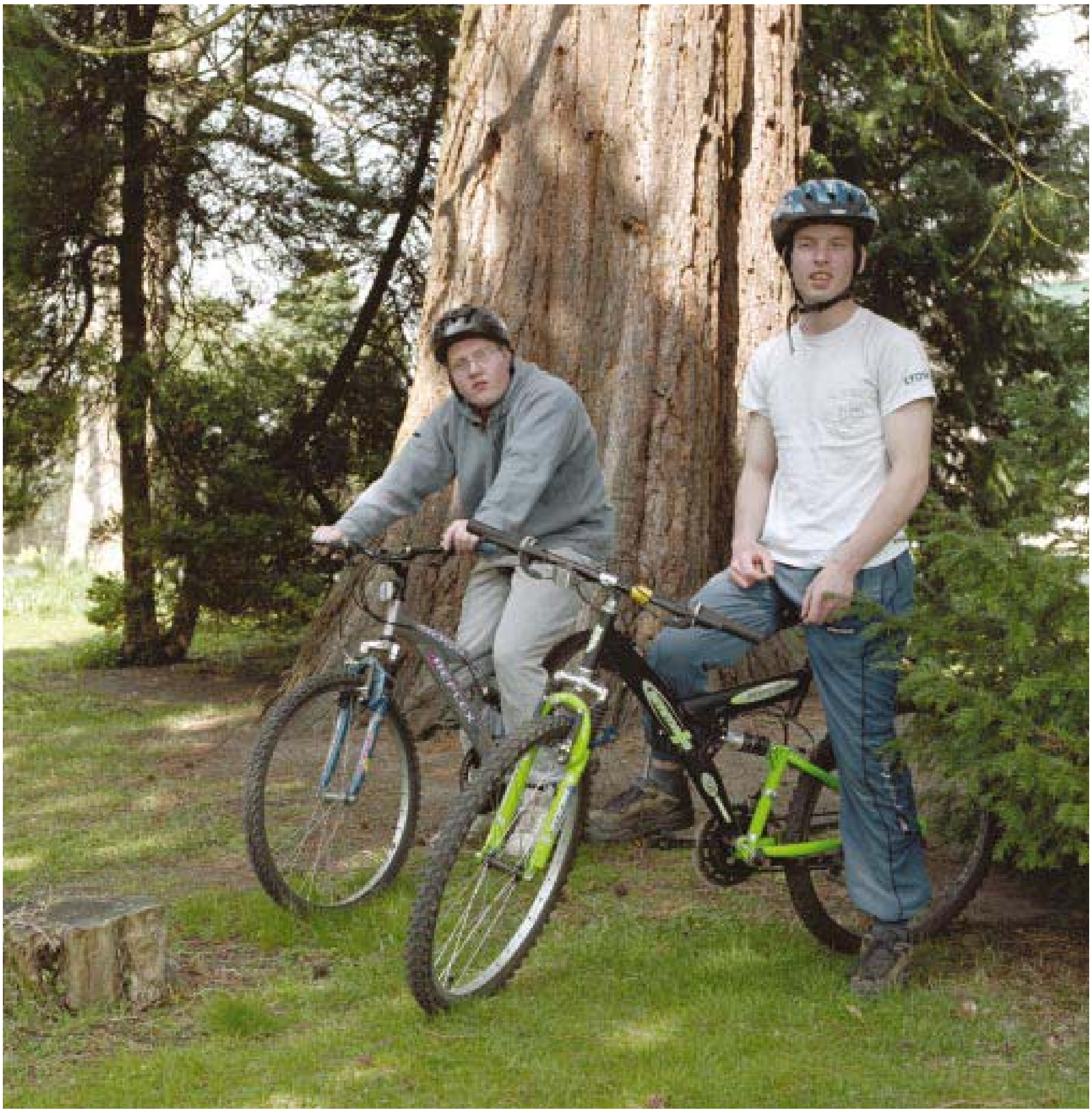
Transport

5.10 Issues and concerns have been raised to the Equal Lives Review about barriers to work and leisure opportunities arising from inadequate transport provision. This includes:

- the particular transport needs of people with a learning disability in rural areas
- the introduction by the Department for Regional Development (DRD) of reduced charges on public transport for people with a learning disability is a very welcome development. Similar reductions for their supporters are being considered.
- provision of transport within health and social services day services consumes over 25% of the total budget. As a consequence of the locations of many day centres, individuals can spend very lengthy periods being transported to/from centres with only 20% of centres able to transport most of their attendees from home to centre in less than 30 minutes.
- given the emphasis on facilitating people to use transport and enabling people with affordable, accessible transport, there also needs to be an emphasis on accessible transport for those with significant needs/complex needs. The cost of buying a suitable vehicle with appropriate modifications to enable a person with a learning disability to travel whilst seated in their wheelchair, whether through Motability or privately, is prohibitive for many families.
- a number of services have developed innovative independent travel training schemes, which have increased the capacity of individuals to make fuller use of public transport.

Leisure

5.11 Many people with a learning disability live lonely lives. Most of their free time is spent in home-based pursuits such as watching television and listening to music with few friends of their own age.



- In a study in 2003 the researchers interviewed the parents of over 50 school-leavers from 2 special schools for pupils with severe learning disabilities in Northern Ireland. Three in five of the young people (58%) were reported to have no friends of their own. In all 90% of parents would like their son or daughter to be more involved with friends of their own age and they mentioned the need for more clubs and for more sports and leisure activities. (63)

- A similar picture emerges for adults. In a 2002 study over 2 in 5 people reported having no friends outside of the day centre they attended and 4 was the most that anyone reported. The most common activities undertaken with friends were going to discos and social clubs, but most of these were organised specifically for people with a learning disability, such as Gateway Clubs. (91)

- A study of 65 persons resettled from a long stay hospital in Northern Ireland into nursing home and residential care found that only 14 people (21%) had regular or frequent contact with friends outside of the residence. This included contact with people in day centres. Only 5 people were reported to meet their friends away from the centres; through visits to the residence (4) or going out with them socially (2) or for shopping (1). Overall, the mean number of different leisure activities residents had engaged in during the past 4 weeks was 5.6. However, people living in nursing homes had a significantly lower mean score (3.1 activities) than those in residential (5.8 activities) or community homes (7.4 activities). (92)

- Overall people with a learning disability tend to lead more sedentary lifestyles than the general population, performing significantly less than the minimum levels of physical activity recommended by the Department of Health. Levels of obesity appear to be rising among adults with a learning disability in Northern Ireland. (93)

- People with a learning disability often express dissatisfaction with their community, recreation and leisure activities. They mention in particular the need for more evening and weekend activities and greater opportunities to take part in community events. Among the obstacles they currently experience are the lack of public transport and the prohibitive costs of taxis, problems with physical access to premises such as cinemas, nightclubs, bars and restaurants and the lack of a companion - befriender - to accompany them. (1)

- Many family carers are also concerned about the lack of leisure opportunities. (56) Among the suggestions they made were:
    - drop in centres and more social clubs
    - weekend or short breaks away
    - befriending schemes with long-term commitments
    - education of the general public about learning disability
    - Community Access/Support Workers to allow individuals to attend events/concerts rather than depending on their ageing parents/carers to take them
    - day centre facilities utilised in the evenings.

- Relatively little monies have been expended by social services in promoting the social and leisure lives of people with a learning disability. Often this has been left to charitable groups (often led by parents and relatives) and they continue to be the main provider of leisure opportunities outside working hours with a heavy reliance on volunteers.

- The main service innovations in this area have revolved around the concept of befrienders; ideally a person of similar age, background and interests recruited to share some of their leisure time with a chosen partner. A Northern Irish survey identified this as the fifth most popular form of voluntary activity with an estimated 80,000 people involved across all client groups. (94)

- A number of dedicated befriending schemes have been set up by a range of agencies in Northern Ireland mostly in the non-statutory sector although as yet there has been no evaluation undertaken of their impact and sustainability.

5.12 Despite the fact that access to social and leisure opportunities is extremely limited for many men and women with a learning disability relatively few resources have been expended in this area. Greater attention to developing people's social networks could pay dividends in other ways by reducing the possible consequences of social isolation including challenging behaviours and depression.

Personal Relationships

5.13 Meaningful relationships, including marriage, and expression of one's sexuality contribute greatly to people's quality of life. The sexual expression and developing sexuality of people with a learning disability is often seen as problematic and not a normal part of growth and development. This ignores the person's rights and the benefits to be gained.

- The subject of relationships and sexuality and the social skills required to form appropriate relationships receive insufficient attention at home, at school and in other service settings.
- The changes in the life stages of people with a learning disability are often not recognised. There is a marked lack of sex education for men and women with a learning disability and lack of guidelines for staff who provide sex education.
- Life stages and general sexual and reproductive health care is not provided. For women in particular issues are not adequately addressed in relation to premenstrual syndrome, cervical and breast screening, sexual health screening, menopause.
- Sexual orientation and preferences often go unnoticed and undetected or attributed to lack of experience, choice or environmental influences.

5.14 Staff members who participated in a consultation exercise as part of the Equal Lives Review highlighted a number of issues pertinent to supporting sexual expression that they feel unable to resolve because of lack of clear legislation, policy and guidelines. These included:

- participants working in residential care settings who expressed feelings of frustration around being willing to support clients in their sexual expression but being hampered by how current legislation is interpreted and implemented through policy
- a perceived need for greater clarity between the Mental Health Order, Sexual Offences Act and Human Rights Act, in relation to service users' rights around sexual expression and the process used to assess capacity to consent
- a need for ongoing training, supervision and support to develop understanding and competencies at different levels of intervention, mostly around inappropriate touch/abusive behaviours
- policies are now more likely to acknowledge the rights of people with a learning disability around their sexuality and sexual expression, however, there is a lack of clarity around whether service users' rights are prioritised above parents' rights and the legal position regarding parents' rights i.e. if there is a clash between the individual's wishes and parents' wishes, whose views should be prioritised?
- balancing rights, responsibilities, vulnerabilities and risk in this area is complex and hampered by apparent lack of clear direction as to the parameters within which staff should work at a practice level.

5.15 We anticipate that the ongoing work of the Legal Issues Committee and of the Office of Law Reform on mental capacity will assist in resolving some of these issues.

5.16 There is a lack of support, education and training for parents, to enable them to identify emergent issues and gain knowledge and skills in supporting their children. Many parents struggle with their own values and beliefs around sexual expression and the desire of young people and adults with a learning disability to form sexual relationships. The following issues have been expressed by parents:

- fears and concerns around lack of support for children particularly when, during times of transition from primary to post primary education, they are seeking to keep their children in mainstream education

- education around appropriate sexual expression. Parents often feel unable to discuss problems with others and are unable to identify appropriate means of support.

- accessing appropriate information to support them to provide sex education for their sons or daughters.

Action Required

5.17 To address the wide-ranging concerns that have been identified a strategy is required that reduces the barriers to community integration and ensures equity of opportunity and social inclusion. Given its responsibility to promote lifelong learning, further education and increased employability the Department for Employment and Learning has a key role in developing such a strategy.

5.18 In Chapter 12 we set out proposals for new organisational arrangements that should oversee the implementation of these recommendations at both a regional and a local level.

5.19 The starting point for improvement must be the work undertaken at the transitions phase. It is alarming to note that despite effective transition planning being a mandatory requirement, so many young people have unsatisfactory experiences during the move from school towards adulthood. This is a key period when opportunities exist for pioneering a new style of service for a young generation of people rather than pursuing an automatic progression from special school to day service. Parents and young people should be targeted and offered a co-ordinated transitions programme that prepares for the transition to adulthood. This must be accompanied by a transitions plan that outlines the individual's interests and needs including vocational training, education and employment, health profile, social supports, leisure, friendships and social development. Transitions planning should begin at 14 years of age and if required appropriate transitions support available until 25 years. In order to achieve this it is recommended that a Transitions Service is developed for each population of 100 - 120,000 which will work with approximately 60 young people to ensure that the transitions programme and plan are addressed by relevant agencies. **(Recommendation 14)**

5.20 It is clear that transitions planning should not occur in isolation of other initiatives designed to increase opportunities for employment, education and other meaningful daytime activities, if we are to avoid falsely raising expectations. Transition Workers will require close working relationships with a number of agencies including schools; special education officers; the Careers Service; vocational training and employment service providers; the volunteer bureaux; voluntary and community groups, as well as employers and the business community. Current work by the Inter Departmental Group on Transitions will provide a positive steer in this regard. The key will then be local arrangements that are robust and reflect shared planning and ongoing monitoring of provision.

5.21 Provision in FE colleges needs to be fundamentally reviewed and tailored better to meet the need of students with a severe learning disability. Education providers must meet their obligations under the Special Educational Needs and Disability Order (SENDO) to ensure that existing policy, teaching, curriculum and facilities ensure that young people with a learning disability are treated as favourably as others in relation to accessing provision. This includes ensuring that there is a culture of inclusion; that prospectuses and other information produced is accessible and that appropriate learning and financial support is available. In addition it is recommended that the FE sector develop new programmes specifically designed to meet the Lifelong Learning needs of men and women with a learning disability. Particular attention needs to be paid to school leavers amongst whom the specific needs of those leaving at 16 should be noted. We suggest that around 270 fulltime places are required in future years for school-leavers and we recommend a further 300 whole-time equivalent places for older students. **(Recommendations 15, 16)**

5.22 There is a need for a radical reconfiguration of existing day service provision based on a progressive shift towards a resource model. As alternative provision develops there should be a reduction in the numbers of people who attend day centres on a full-time basis. It is anticipated that centres will in future be providing a service to men and women with increasingly complex needs who should also be enabled to access opportunities for community integration. Day centres will need to explore the need for developing sites for meeting the particular needs of people with an Autistic Spectrum Disorder and older people. We believe that the potential for day centres to be used as resources to the community is particularly underachieved at present. Partnership with community and voluntary groups should be explored particularly for the development of evening and weekend access to the centres to facilitate other services and community groups.

5.23 The modernisation of day centres will require reallocation of existing resources and additional investment in physical infrastructure and human resources. In order to stimulate the modernisation agenda each day centre should be required to produce a development plan in partnership with attendees, family carers and potential provider partners. The development plan should address as a minimum issues of:

- location
- buildings
- service functions and activities
- people served
- staffing
- transport
- payments made
- developing links to community and other providers
- provision for people with complex needs.

5.24 Future Department of Health, Social Services and Public Safety investments in day services should be targeted at the development of other supported placements including voluntary work and leisure opportunities. There are different models of achieving this and diversity of provision should be encouraged to promote innovative and creative approaches. **(Recommendation 17)**

5.25 In order to enable the proposed reconfiguration of day services and to promote access to the labour market for men and women with a learning disability it is recommended that supported employment services are developed across Northern Ireland. The Disablement Advisory Service should take the lead in reviewing the existing specialist employment provision including the use of its disability programmes by people with a learning disability. In particular the aim should be to have such services available in each area serving a population of 100-120,000 persons. We welcome the recent initiative of the Department for Employment and Learning to reviewing its employment services for persons with disabilities, including those with a learning disability. **(Recommendation 18)**

5.26 The public sector is a major employer in Northern Ireland. Public bodies could play a key role in addressing the barriers to employment experienced by men and women with a learning disability. Attention should be directed towards the process of recruitment for posts in the public sector including the routes into work, reviewing job descriptions, creation of more part-time posts, process used to attract individuals to apply for a vacancy and selection and interview processes.

5.27 The development of policies and practice in these areas in terms of making reasonable adjustments as defined in the Disability Discrimination Act 1996 would help promote equality of opportunity in a most positive manner. **(Recommendation 19)**

5.28 Mainstream vocational training provision could do more to accommodate the needs of school leavers and adults with a learning disability wishing to enter the labour market. The impact of admissions criteria, course content and outcome related funding on access by people with a learning disability should be examined. Improvements should be made in support provided to participants and the training of staff. **(Recommendation 20)**

5.29 The limitations posed by existing transport provision have curtailed access to educational, employment and leisure opportunities. A determined effort is required to ensure that these barriers are removed. There is scope to more actively promote independent travel on public transport and on foot. This should be planned with the support of the family and must feature in schools and college curricula as well as in other support services. In addition those charged with responsibility for public transport must ensure that the particular needs of men and women with a learning disability are incorporated in their strategies. **(Recommendations 21, 22).**

5.30 With the emphasis on facilitating people to use transport and enabling people with affordable, accessible transport, there also needs to be an emphasis on accessible transport for those with significant needs/complex needs. The Motability Scheme requires reviewing to ensure an appropriate, affordable solution for those who need to travel in their wheelchair along with other family members. **(Recommendation 23)**

5.31 Leisure and recreation schemes should be promoted and co-ordinated at District Council level. An audit should be commissioned of leisure and recreation facilities, societies and clubs within their area that serve the wider community as well as people with disabilities. This Directory should be maintained by District Councils and widely circulated to all service providers (including residential services) and family carers. A central point should be created or identified for recruiting volunteer helpers and drivers. Different schemes within District Councils should have shared access to a minibus or people-carriers. Seed monies should be available to initiate new schemes. **(Recommendation 24)**

5.32 Now that all services are expected to have policy guidelines in place on sexuality and personal relationships, there needs to be concerted efforts across all services to make available opportunities for education on these issues and on sexual health. This should be done with the knowledge and support of family carers, but they should not have a sanction on their relative's participation if that is his or her wish. (**Recommendation 25**)

5.33 The issue of bullying that is commonly reported by self-advocates needs to be proactively addressed both in specialist services and the wider community. In the latter instance, the greater involvement of people with a learning disability in educating senior pupils in primary schools and secondary school students has increased the students' awareness of the hurt they cause. Equally people with disabilities should be encouraged to exercise their rights to make complaints to the police or other relevant authority. It should be noted that the draft Criminal Justice Order includes disability within its definition of the grounds for hate crimes. (**Recommendation 26**)

5.34 Objectives 3 and 4	**Recommendations**
Recommendation 14	That Transition services are established for all young people who have a statement to support parents and young people to develop a transitions plan and ensure recommendations are carried through. Careers advice restructuring should support this proposal and provide an ongoing support to 22 years.
Recommendation 15	The Department for Employment and Learning will ensure that revised funding arrangements are in place so that FE Colleges are able to increase significantly the number of full-time places available to students who have a Statement of Severe Learning Disability, to undertake a 3 year accredited course.
Recommendation 16	In order to afford lifelong learning opportunities the Department for Employment and Learning should ensure that revised funding arrangements will enable more part-time places to be created in FE for older students. Access to FE by people with a learning disability should be monitored and we welcome the intention of the Department for Employment and Learning to do so.
Recommendation 17	By March 2007 each Health and Social Services Trust should have produced a costed Development Plan for each day centre they provide or commission.
Recommendation 18	The Department for Employment and Learning, in consultation with other relevant Departments, should promote the introduction of dedicated Supported Employment services across Northern Ireland.
Recommendation 19	Public sector employers should review their recruitment practices, as required by equality legislation to open up employment opportunities for men and women with a learning disability.
Recommendation 20	Department for Employment and Learning should review the use of its employment, skills and disability programmes by people with a learning disability to remove structural barriers to participation and identify how they could promote better outcomes.
Recommendation 21	Department of Education and Department of Health, Social Services and Public Safety should ensure that young people with a learning disability are equipped with skills to use public transport where possible through appropriately targeted independent travel training programmes. Where possible these should become part of the curriculum and continuing education plans for young adults.

Recommendation 22	Department for Regional Development should ensure that the regional transport strategy ensures that people with a learning disability can access local transport.
Recommendation 23	The Motability Scheme requires reviewing to ensure an appropriate, affordable solution for those who need to travel in their wheelchair along with other family members.
Recommendation 24	Access to local leisure and recreational services should be promoted and co-ordinated led by District Councils.
Recommendation 25	Personal relationships education should be available in all services for people with a learning disability with training offered to staff and support to parents.
Recommendation 26	OFMDFM should co-ordinate a policy initiative to reduce the likelihood of bullying experienced by people with a learning disability, both in specialist settings and the wider community, notably schools. The development of anti-bullying strategies would be a positive first step.

ACCOMMODATION AND SUPPORT

Chapter 6

> *Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative and recreational activities. If the stay of a disabled person in a specialised establishment is indispensable, the environment and living conditions therein should be as close as possible to those of the normal life of a person of his or her age.* **UN Declaration on the Rights of Disabled Persons 1975 (51)**

6.1 Shelter and care are basic human needs. Where we live and with whom we live, help to define us as individuals and give us status. The location of our homes often determines the extent of social inclusion that we experience. During much of the last century those people with a learning disability who could not live with their families had to live on a long-stay basis in hospital accommodation or residential facilities. The most recent Review of Policy for People with a Learning Disability (7) clarified as a Government priority, the need to resettle people who were living in hospital. In many cases the accommodation that replaced the hospitals retained many of their features; most obviously sizeable groups of people who were unrelated to each other living together in hostels, care homes and nursing homes with little engagement with local communities. More recently a wider range of housing options have been developed based on more individual responses and located in ordinary buildings in the community. However, the emphasis on resettlement in Government policy has resulted in an imbalance between efforts to secure alternative housing for people living in hospital and the lack of development of supports to those living with their families. Future housing strategy must take account of population trends that evidence that a growing number of people will require alternative housing options and the need to alleviate pressures on family carers who currently provide accommodation for the majority of people with a learning disability in Northern Ireland.

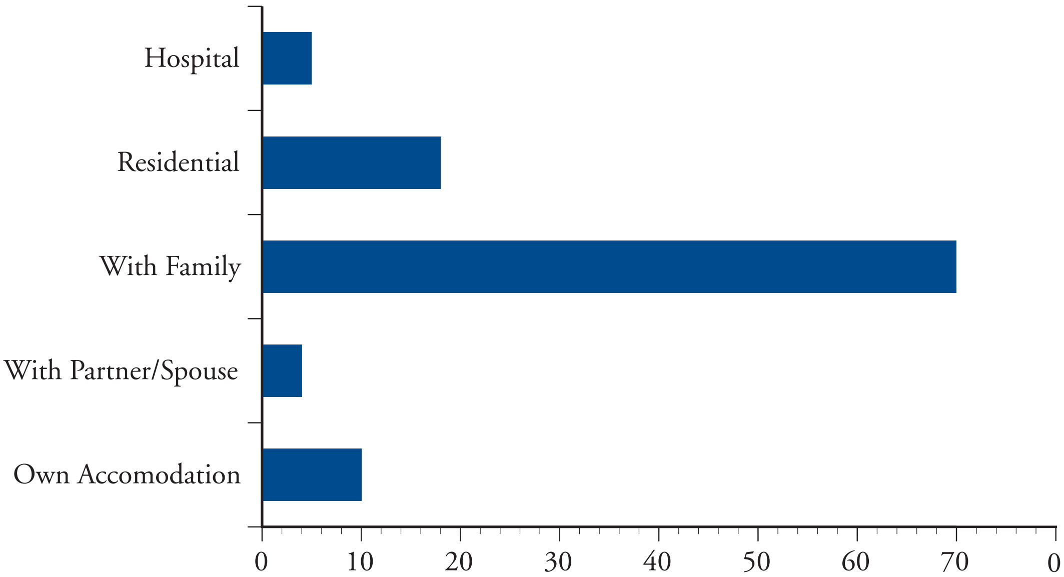
Objective 5	To ensure that men and women with a learning disability have their homes in the community, the choice of whom they live with and that, where they live with their family, their carers receive the support they need.
Objective 6	To ensure that an extended range of housing options is developed for men and women with a learning disability.

Where Do People with a Learning Disability Live?

6.2 Nearly all children (up to 19 years of age) live in family homes either with natural, adoptive or foster parents. (15) Accurate figures are not available for all of Northern Ireland, but in a study in the EHSSB area 34 children were living in some form of residential accommodation and 26 in foster care arrangements. Together these represent 2% of all children known to Health and Social Services Trusts in that area. (73)

6.3 Figure 5 shows where men and women with a learning disability are living.

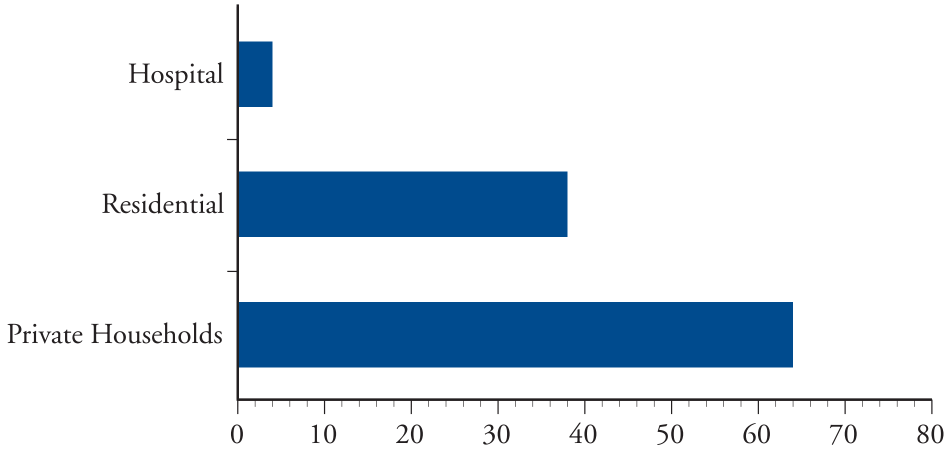
Figure 5: Percentage of adults in different forms of accommodation in Northern Ireland in 2003 (N=7,970) (15)



6.4 As figure 5 shows the majority of people live with family carers although a small proportion have their own accommodation. Around 450 live in hospitals and on average will have lived there for 20 years. Nearly 1900 persons are in some form of residential provision and have lived there for around 8 years on average.

6.5 Comparable figures for Great Britain are given in Figure 6.

Figure 6: Percentage of adults in different forms of accommodation in Great Britain in 1999 (95)



Issues and Concerns

6.6 The main concerns with current arrangements that were highlighted to the Equal Lives Review relate to the position of men and women with a learning disability living long-stay in hospitals, the reliance on large group living arrangements, pressures on family carers and the barriers to developing an appropriate range of housing options.[7]

- Although the number living in learning disability hospitals has been declining since the 1980s, in 2003 it was estimated that 455 men and women with a learning disability had no home outside a hospital: Muckamore Abbey Hospital 300, Longstone Hospital 115 and Stradreagh Hospital 40. (15) This is in spite of the fact that hospital resettlement has been the cornerstone of Government policy in Northern Ireland since 1995. The average age of people living in hospital in Northern Ireland is 49 years. Many have a severe learning disability and more complex needs. They typically live in ward-style accommodation. Few have their own bedroom.

- Research into the resettlement programme has highlighted that people were relocated largely into large group settings with little use being made of more individualised options, such as supported living options. There is also growing concern about what has been termed the *new long stay population* namely those men and women with a learning disability admitted to hospital for assessment and treatment, but who have remained in hospital owing to the absence of a suitable community alternative. Studies have placed this group at between 11 and 15 % of those admitted. (46)

- Approximately half of the remaining men and women with a learning disability who live outside the family home live in registered residential care homes (950 individuals). On average the homes

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[7] Unless otherwise stated the evidence cited in this section is drawn from a series of reports prepared for the Northern Ireland Housing Executive and the 4 HSS Boards by Professor Roy Mc Conkey and colleagues (96, 97, 98, 99)

accommodate 20 individuals. A further 29% live in registered nursing homes. Recent research indicates that approximately 220 men and women might be more appropriately accommodated in supported living options.

- A growing number of people (19%) do live in supported living arrangements where typically they have tenancy agreements and live on their own or with one or two other persons and have support from staff including 24-hour cover if needed. Of those living in these 3 forms of accommodation, the majority came to their present home from living in a hospital (42%) and a further 25% from another residential facility. Only 34% came from the family home.
- Concern has been expressed at the lack of consistency across Northern Ireland in terms of the types and level of provision, which may indicate service inequities. The Northern Health and Social Services Board had the highest proportion of people in nursing home accommodation (46%) as compared with 22% in the Eastern Health and Social Services Board. The Eastern Board had the highest level of people in supported living arrangements (31%) as compared with only 4% in the Western Board and 3% in the Southern Board.
- Most people live with family carers; usually their parents. Nearly one third presently live with a single carer and over 25% with carers aged over 65 years. Around one in 6 carers were rated as being in poor health. These are all risk factors that make present care arrangements vulnerable.
- Families with a disabled member experience far greater problems with their housing than families with non-disabled members. In one study 9 out of 10 families reported at least one difficulty with their housing and many reported multiple problems. (100) Families on low incomes experienced most problems. These include the need for better bathroom facilities and requirements for extra storage space. The report noted that only 10% of families had received assistance from statutory agencies in order to address their housing needs. Families find the process of obtaining grants to improve their homes is complex and time-consuming and often the monies made available are insufficient to cover the cost of the adaptations that are required.
- Carers of people with complex physical and health needs felt particularly unsupported with very limited opportunities for respite breaks and a lack of choice as to alternative care arrangements when they can no longer cope. (2)
- Only a small proportion of people have their own house (around 10%) or live with a spouse/partner (3%).
- More recently a small number of agencies have developed Adult Placement Schemes where families are actively recruited, supported and paid to provide short breaks or long-term homes for selected individuals. Whilst these developments have to date been used successfully in Northern Ireland primarily for short breaks, there is room for further development of the model for the provision of permanent homes. **(101, 102)**

Futures Planning

6.7 The Equal Lives Review has also been presented with a number of issues and concerns linked to planning for future provision that will need to be incorporated in housing strategies developed to address emerging and current needs.

- To date most of the planning has related to the resettlement of people from long stay hospitals. This will continue to be an issue with over 400 people still requiring a move to accommodation in the community. However, the predominance of the resettlement agenda over recent years has had adverse effects in terms of the lack of attention paid to planning for the future housing needs of those who live with families, many of whom are in housing arrangements that are vulnerable to breaking down owing to illness or family crisis. In addition, the type of accommodation favoured during the resettlement programme is not suitable for future needs as men and women with a learning disability increasingly aspire to accommodation arrangements that are more independent and closely integrated into their communities. Large scale, group environments will not meet these aspirations, which will increasingly in the future be driven by awareness of human rights and concepts of social inclusion.

- In addition to those currently living in hospital it is estimated that approximately 1600 persons may require alternative accommodation and/or support arrangements in the coming 5 to 10 years. Of these around 170 are likely to be required in the next 2 years with half of this figure needed in the Eastern Health and Social Services Board area. The amount and type of support varies across individuals, but could involve assistance with personal care, medication, household activities, community participation, budgeting, inter-personal relationships and behaviour management.

- We have identified a number of issues with current administrative systems that threaten the development of more appropriate housing and support options for people with a learning disability:

  - there has been a lack of bridging finance to the same extent as was available in Great Britain to enable people to be resettled from hospitals

  - as yet no commitment has been given to the resettlement of all long-stay patients by a designated date

  - dowry systems are not in place so that the money can follow the resettled person in perpetuity

  - care management procedures as they presently operate, coupled with lack of finance and community options, constrain staff from promoting options for more independent living arrangements and planning for them over a longer time frame

  - men and women with a learning disability, irrespective of where they presently live, are not encouraged by their carers to have their name placed on the waiting lists for public sector housing if a change in accommodation is likely to be required

  - the Equal Lives Review has been made aware that the Common Selection Scheme now operated by the Northern Ireland Housing Executive could make it more difficult for people with a learning disability to access housing that is appropriate to their needs

  - revenue costs for complex needs housing schemes must be secured at the same time as capital costs are committed. This will guarantee that the places are allocated to the persons for whom they were planned. However, revenue allocations by both the Department of Health, Social Services and Public Safety and the Department for Social Development (DSD) are done on an annual basis which prevents planning commitments being given for capital developments that may take up to 3 years to complete.

Action Required

6.8 We propose that the following service principles and aspirations should guide the development of future housing and support options for people with a learning disability. They arise from existing legislation, recent research findings undertaken with this client group and recognised good practice already taking place in Northern Ireland and elsewhere in these islands. They also take cognisance of recent and future legislative changes such as the Disability Discrimination Act and the proposed introduction of a Bill of Rights.

- People with a learning disability have the right to the same range and standards of accommodation that is available to their non-disabled peers.
- They have the same rights as other citizens in obtaining tenancies in public housing, in buying and inheriting houses and in claiming housing and other support benefits to which they are entitled. This includes access to Direct Payments and the Independent Living Fund.
- At present, families provide homes and support for the great majority of people with a learning disability in Northern Ireland. Moreover it is the wish of many people to continue living within the family. Hence families should be supported in continuing to provide housing and support to their relatives as long as both parties wish this to happen. This support should include the provision of housing adaptations, of domiciliary supports and of short breaks.
- People with a learning disability should be enabled to remain in their neighbourhoods if they want to when family carers are no longer able or available to look after them. They should be assisted to continue living in the family home by having tenancies transferred to them; participating in the right-to-buy schemes or the ownership of the house being passed over to them. Domiciliary supports should be made available to the person with a learning disability as well as to family carers.
- Meeting the accommodation and support needs of people with a learning disability is not just the responsibility of health and social services. Hence Health and Social Services Boards and Trusts must work in partnership with a range of statutory and non-statutory housing and social care agencies in order to fulfil these needs.
- A range of different types of accommodation and support services should be available within Northern Ireland so that services can be better tailored to the needs of individuals and to provide for an increased element of choice. People with a learning disability, their relatives and paid carers should be informed about the range of accommodation and support options that are available. This should be done in accessible formats.
- When demand for accommodation and support services exceeds supply, the allocation of these services should be done in a transparent and equitable manner. Applicants, their family carers and advocates must be kept fully informed throughout.
- People should not live in hospital accommodation. Some may have to be admitted for short periods (of up to 6 months) of acute assessment and treatment, but no one should remain there for long periods (12 months+) due to their specialist needs. Everyone should have a home address to which they will be discharged.

6.9 Resettlement of long-stay patients from hospitals within the context of supported living principles must be progressed as rapidly as possible. By June 2011, all people living in a learning disability hospital should be relocated to the community. Funds need to be provided to ensure that on average 80 people will be resettled per annum over the 5-year period from 2006 to 2011. **(Recommendation 27)**

6.10 In order to address the concerns raised about the potential for developing a new long stay hospital population all commissioners should ensure that they have arrangements in place to provide emergency support and accommodation for persons with a learning disability. Learning disability hospitals should not provide this service from 1 January 2007. **(Recommendation 28)**

6.11 Objective 5 Recommendations

Recommendation 27	By June 2011, all people with a learning disability living in a hospital should be relocated to the community. Funds need to be provided to ensure that on average 80 people will be resettled per annum over the 5-year period from 2006 to 2011.
Recommendation 28	With immediate effect, all commissioners should ensure that they have resourced and implemented arrangements to provide emergency support and accommodation for persons with a learning disability. Hospitals will not provide this service from 1st January 2008.

6.12 In line with the thrust towards more normal, individualised housing options for men and women with a learning disability there is a need for both a wider range of supported living provision, to include adult placement services, and to address the deficiencies identified in large-scale group living environments. New care standards coming into force over the next 3 years will require upgrading of much current provision. This is not only to improve the quality of life of existing residents, but also to secure better quality provision for future users of these accommodation options. We propose that in future all new-build accommodation provided for people with a learning disability should be for no more than 5 individuals - preferably less - within the same building. This accommodation should take the form of lifetime, barrier-free homes, i.e. homes that can provide security of tenure for the tenants and be designed in such a way as to be suitable for meeting the needs of current and potential physical disabilities. In order to assure equity of provision it is also proposed that by January 2013 all accommodation provided for men and women with a learning disability and aged under 60 should be in households of 5 or less individuals. **(Recommendations 29, 30)**

6.13 In order to meet the emerging needs identified an additional 100 supported living places per annum for the next 15 years should be developed to enable people to move from family care without having to be placed in inappropriate settings. **(Recommendation 31)**

6.14 These proposals will require close collaboration with the NI Housing Executive, Department for Social Development and health and social services agencies. There should also be active engagement with personnel from the Social Security Agency at both regional and local levels. Mechanisms should be put in place to engage with District Councils, Local Health and Social Care Groups and community organisations in the development of local initiatives. In particular funding mechanisms and planning cycles urgently need to be addressed in order to enable the extensive programme of work that is required. The capital and revenue cycles of both Department of Health, Social Services and Public Safety and Department for Social Development need to synchronise for Supporting People schemes. **(Recommendation 32)**

6.15 In particular when considering the needs of people with more profound and multiple disabilities the potential for technological advancements in maximising opportunities for independence needs to be more fully harnessed. Housing planners and service providers should improve their awareness of such developments and their application within future housing strategies. **(Recommendation 33)**

6.16 The Equal Lives Review has highlighted the low level of home ownership amongst men and women with a learning disability in Northern Ireland. It should be clarified if Supporting People monies can be used to support people who are owner-occupiers. There is considerable scope for meeting at least some of the emerging housing needs through Supporting People to either purchase their own homes or to take over the ownership of property left to them by families. **(Recommendation 34)**

6.17 Improved supports need to be given to family carers to enable people to continue living with their families. This includes improved short break provision; extension of home based, floating support services to maintain people in family homes; support for other family members to take over the caring role from ageing parents if they wish to and improvements to the process of accessing housing adaptation grants. **(Recommendation 35)** The Department for Social Development and the NI Housing Executive should ensure the increased use of floating support linked to an individual's needs rather than overly relying on accommodation based schemes. This would make it easier for people to move to more suitable accommodation as their needs change. **(Recommendation 36)**

6.18 Objective 6 Recommendations

Recommendation 29	With immediate effect, all new housing with support provision for people with a learning disability should be for no more than 5 individuals with a learning disability - preferably less - within the same household.
Recommendation 30	By 1 January 2013 all accommodation for people with a learning disability under 60 years of age should be for no more than 5 people.
Recommendation 31	An additional 100 supported living places per annum for the next 15 years should be developed to enable people to move from family care without having to be placed in inappropriate settings.
Recommendation 32	Department for Social Development and Department of Health, Social Services and Public Safety should develop clear assessments of future housing needs for people with a learning disability including those who currently live with their families and agree a continuous 3 year funding strategy to resource housing and support arrangements.
Recommendation 33	Housing planners should accumulate and disseminate detailed knowledge on the range of assistive technology that is available to enrich the capacity of people with a learning disability to lead more independent lives in the community.
Recommendation 34	A strategy should be developed by the Department for Social Development to increase opportunities for people with a learning disability to own their own homes where this is a safe and appropriate option.
Recommendation 35	Procedures and criteria for applying for Disabled Facilities Grants should be revised to tackle inconsistencies, reduce bureaucracy and reduce the hidden costs to carers.
Recommendation 36	Department for Social Development and the NI Housing Executive should establish mechanisms to ensure the increased use of floating support linked to an individual's needs rather than overly relying on accommodation based schemes.

HEALTH AND WELL BEING

Chapter 7

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity **World Health Organisation 1946 (103)**

Health is a fundamental human right **DHSSPS 2002 (104)**

7.1 An increasing number of people with a learning disability are living longer and healthier lives. Greater numbers of children with complex health needs and multiple disabilities are surviving into adulthood. Increasingly people with a learning disability who experience mental health problems are living in local communities rather than having their homes in specialist hospitals.

7.2 In order to ensure that people with a learning disability enjoy the benefits of such changing circumstances, commissioners and service providers will need to actively ensure that there is equity of access to the full range of healthcare provision enjoyed by the general population. This is now clearly enshrined in human rights and equality legislation. Evidence presented to the Equal Lives Review demonstrates that there are both high levels of unmet health needs and deficiencies in the current systems for ensuring that the physical and mental health needs of people with a learning disability are effectively addressed.

7.3 In this chapter we will outline the key issues and concerns relating to the physical health of people with a learning disability. A coherent strategy is then proposed to address the concerns based on the Equal Lives Values and those principles that currently inform public health policy. Chapter 8 will address issues related to mental well-being and challenging behaviours.

Objective 7 To secure improvements in the mental and physical health of people with a learning disability through developing access to high quality health services that are as locally based as possible and responsive to the particular needs of people with a learning disability.

Issues and Concerns

7.4 Research has consistently confirmed that the life expectancy of people with a learning disability has increased markedly over the last 60 years. One study reported an increase in the average age of death between 1931 and 1995 of 53 years for men (from 14.9 - 67.2 years) and 47 years for women (from 22 - 69.2 years). (105)

7.5 However, the research evidence also indicates that people with a learning disability have higher mortality rates than people in the general population. (106, 107)

7.6 Some people with a learning disability are at higher risk of physical ill health arising from problems associated with particular conditions or syndromes: (42, 108, 109, 110)

- physical and sensory impairments are more frequent amongst people with a learning disability
- they may also develop further difficulties related to cardiovascular problems, resistance to infections and their immune systems
- there is an increased prevalence of physical and sensory impairments amongst people with a learning disability
- there is an increased prevalence of epilepsy which occurs within 25% of people with a learning disability and 1/3 of people with profound learning disability
- there are significantly higher levels of obesity
- increasing numbers of people with a learning disability require intensive nursing care and technological support owing to complex health needs, have higher risk of infection or respiratory difficulties.

7.7 On occasions individuals may be so vulnerable and have such complex needs that they lack full insight into the degree of support required to keep themselves physically and mentally well. The Legal Issues Committee is addressing this issue in detail in the context of capacity.

7.8 Northern Ireland studies were at the forefront in identifying the high levels of undetected health problems amongst people with a learning disability, some of which are easily remedied such as impacted ear wax. Often the problems remain undetected for long periods until they become serious and more obvious.

7.9 The oral health of people with a learning disability is worse than the general population with poorer oral hygiene, higher untreated diseases and more extractions. (111, 112) This was an area of particular concern to family carers during consultation events (2) and is the subject of a separate review being undertaken by the Department of Health, Social Services and Public Safety.

7.10 In December 2004 the Disability Rights Commission launched a formal investigation into health inequalities experienced by people with long-term mental health problems and people with learning disabilities in England and Wales. The investigation, which is titled Equal Treatment - Closing the Gap, has been launched because of the overwhelming weight of evidence pointing to disparities in health outcomes amongst people with learning disabilities and people with long-term mental health problems. Put simply, a lot of evidence points to the fact that these groups of people have higher morbidity and mortality rates than the overall population, and not always due to reasons related to their disability. Therefore the Disability Rights Commission has decided to use its powers to undertake formal investigations to instigate a comprehensive enquiry into this issue.

> *My daughter has been waiting since January (11 months) to get 2 bad teeth removed. No reasons have been given to me to explain why the delay. She is suffering and in constant pain. She should not have to go through this.* (2)

7.11 Primary care services are the first point of contact for many family carers and people with a learning disability in seeking help with health concerns. For many the family GP has a very significant role. Where a GP has a good relationship with families, s/he can have a very positive influence on the healthcare experiences of both the family and the individual with a learning disability. (2) However, while this is the case in many instances, a number of concerns have been identified.

- Many people with a learning disability make less use of their GP. (113) In a study in the Western Health and Social Services Board area 44% of GPs and 63% of nurses reported that people with a learning disability used the practice less often than other patients. (114)

- GPs can have limited confidence about their role in meeting the health needs of people with a learning disability. (113, 115)
- There is a limited uptake of health screening by people with a learning disability. (116, 117)
- Difficulties have been reported in attempts to identify people with a learning disability on general practitioner registers for the purpose of health screening, as no system exists for such purposes. In a survey in the WHSSB area 51% of GPs reported that they could not easily identify people with a learning disability. (114)
- Confusion exists about the roles and responsibilities between specialist learning disability services and mainstream health services in relation to the health care of people with a learning disability. However, where they do work together health status can be improved. (113)

7.12 In the past people with a learning disability who required hospital treatment arising from a physical health problem were sometimes admitted to specialist learning disability hospitals. The inappropriateness of this practice was recognised and Government policy now emphasises the rights of all to access mainstream health services including acute hospitals. The Equal Lives Review was informed about a number of positive initiatives in Northern Ireland acute hospitals to facilitate people with a learning disability including one hospital making arrangements to reduce waiting times in hospital and the provision of accessible information in another. However, consistent feedback from our consultations indicated that in many instances acute hospital staff require staff from the learning disability service or a family member to be present all the time on the ward when the patient is in hospital. As yet there has been limited study of the extent of contact that people with a learning disability have with acute hospitals or the quality of their experiences.

7.13 Findings from a study in Northern Ireland provide some indication of the position: (118)

- people with a learning disability have regular contact with acute general hospitals
- limited use is made of opportunities for the use of pre-appointment/pre assessments and advance planning
- at admission time limited steps are taken to accommodate the individual abilities and the needs of the person with a learning disability
- people with a learning disability are often excluded from key discussions and decisions about their care
- further training is required by hospital staff in relation to requirements for obtaining informed consent from people with a learning disability
- nursing staff have limited knowledge and skills in relation to communicating and managing people with a learning disability
- the majority of parents and carers perceived the need to remain in hospitals for the duration of contact in order to ensure the person with a learning disability received adequate care and supervision
- acute hospitals may need to provide ongoing support if treatment is to be completed successfully and to avoid premature discharge
- more effective liaison arrangements between acute hospitals and learning disability services need to be put in place
- there is a need for further training of staff to work with people with a learning disability in acute hospital settings.

7.14 These findings are similar to others, which have been reported by people with a learning disability and family carers from elsewhere in Northern Ireland. (1, 2, 119)

7.15 During the Equal Lives Review we also learnt of many excellent initiatives in Northern Ireland designed to improve the health status of people with a learning disability. These include research, health screening projects, production of accessible health information and health promotion initiatives.

7.16 Unfortunately many of these initiatives have been ad hoc, project based and time limited owing to funding constraints. Therefore, while they have benefited local groups, they have had limited impact on the regional health status of people with a learning disability. (40, 41, 42)

7.17 Despite increased emphasis on health promotion issues in Government and health service policies there is little evidence of specific targeting of people with a learning disability within Northern Ireland. This contrasts with the position in England, Scotland and Wales where specific guidance and policy has been produced. (120, 121)

Access to Specialist Services

7.18 People with a learning disability should have access to the wide range of specialist health care services available in the community including neurology services, epilepsy nurse specialists and diabetes nurse specialists.

7.19 The creation of Health Facilitator posts in England has enabled more people with a learning disability to have access to this range of services while supporting such services to develop the necessary skills to meet their needs. Although the term is new, Health Facilitation is not a new concept and can be used to describe anyone who is assisting a person with a learning disability to achieve and maintain good health. Indeed Health Facilitation is a central component of each professional working in any field. However the formal recognition that named Health Facilitators are receiving is new, together with the opportunity to act on a strategic as well as a local level. Health Facilitation evolved from roles developed by carers, practitioners and others who were concerned about improving the health of people with a learning disability through the NHS in order to access the best and most appropriate health care.

Aids To Daily Living

7.20 Evidence presented throughout the Equal Lives Review confirms that there will be a marked increase in the number of children, men and women with complex physical health needs and disabilities.

- Timely access for necessary equipment must occur to prevent long waiting times that often cause extreme physical hardship.

- On average each disabled child in Northern Ireland uses three pieces of specialist equipment each day as an aid to daily living. Families often report long waiting times between assessments and delivery, problems with repairs and needs changing over time not being assessed. Much energy is expended by families in accessing these vital practical aids which can lessen burdens associated with mobility, continence, feeding and sleeping. The absence of these at the right time increases stress on the family unnecessarily. (79)

Action Required

7.21 In 2002 the Ministerial Group on Public Health launched a new public health strategy Investing for Health, which sets out the way forward in making improvements to the health of the population in Northern Ireland. (104) Investing for Health adopted 4 key values:

- health is a fundamental human right

- policies should actively ensure equality of opportunity and promote social inclusion

- individuals and communities should be included fully in decision-making on matters relating to ill health
- all citizens should have equal rights to health, and fair/equitable access to health services and health information according to their needs.

7.22 Whilst the specific health needs of people with a learning disability receive limited attention, it is noted that people with disabilities are entitled to the same access to opportunities as their non-disabled peers. In order to ensure that the outcomes of Investing for Health benefit people with a learning disability, determined action will be required to reduce the inequalities in health and service provision that currently exist.

7.23 An effective strategy should include the following:

- a priority theme of ensuring that the health needs of people with a learning disability are better served by mainstream health services in the first instance
- improving collaboration between primary health care staff and learning disability services
- optimising the contributions of learning disability expertise in achieving health gains but reshaping their contribution to achieve improved health outcomes and access to mainstream services. The role of professionals in learning disability services should develop to enable them to build new relationships with mainstream colleagues, improve the knowledge base of mainstream staff and reshape their contribution to service provision.
- ensuring that the small number of individuals with complex health needs and additional disabilities whose needs cannot be effectively managed by mainstream services receive ongoing and intensive support from specialist professionals to ensure their needs are met
- reshaping the workforce and meeting a wide range of staff training and development needs (This will be explored further in Chapter 11).

7.24 Despite the clear evidence on unmet health needs amongst people with a learning disability limited attention has been paid to these issues in either Departmental or Health and Social Services Board/Trust policy documents. This fails to acknowledge the particular support needs of many people with a learning disability in relation to accessing health care services and health promotion initiatives.

7.25 In order to make a long-term and sustained improvement to the health status of people with a learning disability there is a need for a regional approach to health improvement. This is particularly crucial in view of the evidence that where targeted action has been taken in specific localities, positive outcomes have been demonstrated.

7.26 It is recommended that the Department of Health, Social Services and Public Safety establish a regional framework for sustained health improvements of the learning disabled population. **(Recommendation 37)** The regional framework should include:

- clear statements on the rights of people with a learning disability to have equality of access to health care under recent legislation and Government policy directives
- specific targets in relation to registration of people with a learning disability with general practices and other relevant family practitioners e.g. dentists

- expectations of health checks and health screening for people with a learning disability with particular reference to key areas that have particular risks e.g. cervical/breast screening, thyroid function tests for people with Down's Syndrome
- specific health promotion initiatives and interventions that focus on improving the health status of people with a learning disability in key areas such as nutrition, obesity, exercise and dental health
- requirements in relation to production of Health Action Plans
- requirements for health promotion initiatives to take account of the particular difficulties experienced by people with a learning disability in accessing information.

7.27 It will be necessary for each Board to review existing Health Improvement Plans for people with a learning disability to ensure that they translate the regional framework at a local level.

7.28 In order to redress the lack of attention given to the particular health issues in policy documents it is recommended that all generic health strategies make specific reference to the needs of and impact on people with a learning disability alongside other minority groups. **(Recommendation 38)**

7.29 In order to support the major practice, organisational and cultural changes required it is recommended that the new role of Health Facilitator be created. The primary role and function of Health Facilitators would be to drive and champion the implementation of the regional framework, support work to achieve the local targets and establish Health Action Planning processes for priority groupings within the population of people with a learning disability. **(Recommendation 39)**

7.30 The Health Facilitator's role would embrace both physical and mental health needs and ensure that people with a learning disability gain full access to the healthcare they need for both primary care and acute hospital services.

7.31 In order to ensure that the specific individual health needs of people with a learning disability are identified and addressed it is proposed that arrangements be set in place to ensure that all are offered a personal Health Action Plan. Health Action Plans detail the actions that are required to maintain and improve the health of people with a learning disability . They encompass a personal plan that outlines the help needed to enable a person with a learning disability to stay healthy, responsibility for which will rest with a named Health Facilitator working in partnership with primary health care staff. Health Action Plans involve people with a learning disability and their family carers in effective multi-agency and multi-disciplinary care planning prepared with and for the individual concerned. The Health Action Plan where possible should form part of a Person Centred Plan. In order to reduce the inconsistencies that can result from local initiatives it is recommended that the broad format for the Health Action Plans be agreed at a regional level. **(Recommendation 40)**

7.32 Health Action Plans should include details of the need for health interventions, oral health, fitness and mobility, emotional needs and records of screening tests. They should also identify clearly who is responsible for taking action.

7.33 Further action is required to raise awareness with primary care services and acute general hospitals of the health issues faced by people with a learning disability. In order to clarify arrangements and ensure that roles and responsibilities are clearly set out between mainstream and specialist learning disability services it is recommended that each general practice and acute general hospital develop clear arrangements to facilitate equality of access for people with a learning disability. **(Recommendation 41)**

7.34 As noted earlier identification of people with a learning disability at primary care level is problematic. Without such identification targeted efforts to improve involvement in health screening and planning for provision is not possible. It is therefore recommended that improvements be made in how people with a learning disability are identified within GP practices (e.g. use of standardised diagnostic codes throughout Northern Ireland). This would have a number of benefits including:

- raising awareness of poor health status and consequent need for practices to focus attention on them
- identification of specific physical and mental health issues that might be targeted locally
- provision of a basis for target setting, monitoring and evaluation. **(Recommendation 42)**

7.35 It is recognised that GPs and other practice staff may require support from specialist learning disability professionals to assist them in providing sensitive and appropriate services. There is a need for Community Learning Disability Teams to more closely align themselves with primary care colleagues. We propose that this be achieved by the development of having a named professional from the Community Learning Disability Teams linked to each GP practice. The link person may be able to resolve some of the common problems experienced by individual people with a learning disability in using primary care services including long waiting times, medication management, communication difficulties. The link person could have a role in:

- practice training sessions in health centres to improve knowledge of learning disability and physical/mental illness
- developing effective partnership work between primary care and learning disability services
- assisting in health promotion initiatives provided for people with a learning disability. **(Recommendation 43)**

7.36 An essential component of supporting optimum physical health is adequate management of associated physical disabilities. To meet the increasing quantity and complexity of needs high specification equipment must be available. The range of wheelchairs and aids available through the Regional Disablement Service should be appropriate to individual need and the budgets will need to be reviewed to reflect the anticipated increase in demand. **(Recommendation 44)**

7.37 Objective 7 Recommendations

Recommendation 37	The Department of Health, Social Services and Public Safety should produce a Regional Framework for Health Improvement of people with a learning disability providing clear direction including targets and timescales. Each HSS Board should review their Health Improvement Plans to ensure that they translate the regional framework at a local level to support improved health outcomes for children, men and women with a learning disability.
Recommendation 38	All generic health strategies, published at Department, Board and Trust level, should make specific reference to the needs of and impact upon people with a learning disability.
Recommendation 39	By December 2009 resources should be made available from within primary care to appoint within primary care a Health Facilitator for each 110- 120,000 population.

Recommendation 40	By December 2008 a Health Action Plan will be developed, as a part of the Person Centred Planning process, which is to be set in place for all those with a learning disability in contact with health and social services agencies.
Recommendation 41	With immediate effect each general practice facility and acute general hospital within Northern Ireland should have clear and formalised arrangements in place to facilitate equity of access to services for people with a learning disability.
Recommendation 42	Each general practice should establish robust medical records and health data about people with a learning disability on their practice register.
Recommendation 43	With immediate effect each general practice should have an identified link person within their local Community Learning Disability Team with whom they work collaboratively to facilitate better access for people with learning disability within primary care settings.
Recommendation 44	Equipment and wheelchair provision budgets should be increased to meet significant additional demand. This will require an increase of the proportion available to people with a learning disability.

MENTAL HEALTH AND CHALLENGING BEHAVIOURS

Chapter 8

> *Mental Health is the emotional and spiritual resilience, which enables us to enjoy life and survive pain, disappointment and sadness. It is a positive sense of well being and an underlying belief in our own worth and others' dignity and worth* HEA 1998 cited in Promoting Mental Health DHSSPS (2003) (122)

8.1 Promotion of mental health is of particular importance for people with a learning disability. Mental health problems are much more frequent among people with a learning disability. The presence of a mental health problem combined with a learning disability makes it even more difficult to cope independently and to make balanced decisions about life and care. In this chapter we will focus on the mental health needs of people with a learning disability and the action required to address them in order to fully achieve Objective 7.

Objective 7 To secure improvements in the mental and physical health of people with a learning disability through developing access to high quality health services that are as locally based as possible and responsive to the particular needs of people with a learning disability.

Issues and Concerns

8.2 People with a learning disability can experience the same range of mental heath problems as the rest of the population and there is evidence that they are more prevalent amongst this group. (123, 124)

8.3 Reported prevalence rates vary widely, for example, schizophrenia is three times more common than in the general population. (125)

8.4 There are difficulties in recognising that a person with a learning disability has a specific mental illness and underreporting of mental health problems can occur. (126)

8.5 Within Northern Ireland there is expertise in assessing and treating mental illness in people with a learning disability. This is best evidenced where a number of professionals can work in an inter-disciplinary way. This presently occurs in the three specialist hospitals. There has been limited development of this comprehensive approach in community settings. Access by people with a learning disability to mainstream mental health services is extremely limited. An unhelpful barrier based on IQ currently determines an individual's access to services.

8.6 Many community residential facilities in Northern Ireland have difficulty in providing the specialist support required by people with complex mental illness. They rely on the expertise of outside professionals and admissions to specialist hospitals are higher from these settings than from people living with family carers. (46, 47)

8.7 Health and social services are only in the early stages of developing specific community based services within learning disability services to support people who develop major mental health problems, although some professionals have developed a high degree of specialism while addressing the needs of individuals with whom they work. (127)

8.8 Improved collaborative planning or joint work between specialist hospitals and community based services is a priority.

Challenging Behaviours

> *Severely challenging behaviour refers to culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.* **Emerson (128)**

8.9 Challenging behaviours may be associated with a mental health problem. They may also be used by an individual:

- to indicate pain or distress
- as a means of communication
- to avoid stressful situations
- as learned behaviours triggered by specific contexts.

8.10 Challenging behaviours can present major difficulties within services and potentially are a significant obstacle to securing the inclusion of individuals in community based opportunities. It is difficult to be certain about the number of people with a learning disability who display severe challenging behaviours largely because of different definitions that have been used. However, research conducted in Northern Ireland indicates that it is a major issue in both community and hospital services.

- Behavioural management was reported as being the third most frequently reported role of community nurses for people with a learning disability. (129)
- Another study of caseloads of all community nurses for people with a learning disability in Northern Ireland found that 28 % of people they work with were reported to have challenging behaviours. (130)
- 70% of people admitted to Longstone hospital over an 18-month period were noted to have challenging behaviour. (127)
- In a study of 154 people admitted to Muckamore Abbey hospital the most common reason for admission was that of a wide range of challenging behaviours (69%). (131)

8.11 The consequences of challenging behaviours can be serious in terms of impact both on the individual involved and on others including:

- people who display challenging behaviours may suffer severe harm due to self-inflicted behaviours

- people with challenging behaviours are more likely to be socially rejected and excluded. This is particularly the case for people with communication difficulties for whom social integration is further reduced. (132)

- parents of children with a learning disability and challenging behaviours have high levels of personal stress and increased social isolation (133)

- sleep disturbance has been reported in 88% of children with challenging behaviour (134)

- staff in services in Northern Ireland have cited issues related to challenging behaviour as a key unmet training need and have highlighted their disquiet at the lack of clear guidance on appropriate methods of working with people whose behaviour is challenging (135, 136)

- the individual may come into contact with the police and criminal justice system.

8.12 There is expertise in the assessment and management of challenging behaviours within hospitals and in community teams. Strategies that have proven successful in addressing challenging behaviours include:

- Applied Behavioural Analysis

- manipulation of the living environment

- education for carers and families.

Action Required

8.13 In addition to the action detailed in Chapter 7 with regard to health promotion, health facilitation and primary care services, we believe that a new model based on community provision is required to address the needs of men and women with a learning disability who have mental health problems and/or display challenging behaviours.

8.14 Other Expert Working Committees of the Review of Mental Health and Learning Disability (NI) will address:

- **forensic issues** especially the interface between mainstream forensic mental health services and specialist learning disability provision in the areas of prevention, continuity of care as well as in specialist assessment and treatment. Individuals with a learning disability can be particularly vulnerable when in contact with the criminal justice system. This can occur in police stations, when attending court, in prison and young offenders centres and on probation. There must be a full range of inpatient care, including high, medium and low security services. In addition there is a need for Community Forensic Services to support the full range of people with a learning disability in the community, including those who have been discharged from hospital or released from prison. Detailed consideration of the needs of people who require the support of specialist forensic services will be included in a separate report.

- **child and adolescent mental health.** We anticipate that mainstream services will take the lead role for those with a mild and moderate learning disability with joint working becoming more common for those with a more severe learning disability.

- **alcohol and substance misuse.** Amongst people with a learning disability who have problems with substance misuse or alcohol problems, most will have a mild learning disability. The combined problems of substance misuse with a learning disability, possibly with an additional mental health problem, greatly increases concerns regarding vulnerability and the capacity to make informed life choices. Mainstream addiction services require an individual to have a high level of motivation and a desire for change to benefit from treatment. People with a learning disability need particular support to assist them to take part in such treatment when their capacity to make informed life choices is impaired. Specific recommendations regarding development of this aspect of the service are contained in the report from the Alcohol and Substance Misuse Committee.

- **mental health promotion.** It is clear that both children and adults with a learning disability are exceptionally vulnerable to mental health problems and as a result of this vulnerability, there has been an impetus towards detecting, assessing and treating mental health problems in this population. Such an impetus, whilst very necessary, is reactive by its nature, and a key message is that little attention has been given to the development of robust proactive and preventative strategies that build resilience and protect people with a learning disability from the development of mental health problems. Emphasis should be given within all relevant sectors to building positive mental health from childhood onwards. Schools and colleges in particular have immense potential to contribute to and enhance young people's emotional development.

- **mental health issues in old age and dementia.** Service developments and provision that have been found to be helpful with the general population need to be applied within learning disability services. We anticipate joint working arrangements to be common practice.

- **legal issues.** Issues such as guardianship, capacity, compulsory admission for assessment and treatment, the Mental Health Review Tribunal, advocacy, legal representation, indeed what type of legislation should replace the existing Mental Health Order (NI) 1986 are all matters which clearly affect people with a learning disability and will be addressed by the Legal Issues Committee.

8.15 The Expert Working Committee on Adult Mental Health has incorporated proposals for addressing the mental health needs of people with a mild learning disability in mainstream mental health services which supports the model of provision which follows.

8.16 Simply having a learning disability has been enough to exclude people from accessing services. We suggest that a collaborative system of care between mental health and learning disability services will best meet the needs of this most vulnerable group. Historically in Northern Ireland more individuals with mild/borderline IQ levels did access mainstream services. However over recent years this practice has been diminishing.

8.17 A significant proportion of adult admissions to specialist learning disability hospitals are people with a mild/moderate learning disability. Many of these admissions could be prevented if appropriate community supports were in place. People with a mild learning disability should be able to access mainstream mental health services where these services are appropriate to meet their needs. Mainstream services include child and adolescent mental health services, mental health services for adults of working age, mental health services for older people, forensic mental health services, substance misuse services, brain injury services etc. The benefits of this approach include facilitating access to a wider range of expertise and increased access to local services. It is recognised that achieving this shift may initially give rise to clinical concerns about the quality of the experience for the individual. However, these concerns will be reduced if adequate energies are directed towards increasing the collaboration between learning disability services and mainstream services and to developing protocols whereby the skills of learning disability specialists are appropriately shared across programmes. **(Recommendation 45)** In order to achieve this it would be necessary to greatly strengthen links between learning disability services and mainstream mental health services. **(Recommendation 46)**

8.18 In order to address the low level of community provision and the consequent over dependence on hospital based interventions it is proposed that community based assessment and treatment services be further and more robustly developed. These should be built on existing professional expertise. Training that involves the sharing of skill and knowledge across the range of professionals can enhance expertise.

8.19 A model for community service would include community assessment and treatment teams who would be competent in addressing mental health problems and challenging behaviours. Crucially the teams should provide an outreach service to homes and services in the community and be available outside of normal office hours. Such a community service would include a range of accommodation options providing a variety of supports. It is proposed that such services be developed incrementally in order to enable an appropriate remodelling of current hospital provision and the development of appropriately piloted protocols, eligibility criteria and operational systems. The regulatory status of this provision will also need to be clarified, as it will be a new service model that does not readily fit with current regulation categories.

8.20 Outcomes and benefits of this model are:

- a local, safe, secure alternative to acute hospital admission
- easement on demand for hospital admission
- reducing length of stay of hospital admission
- continuity of normal lifestyle pattern through continued community integration
- maintenance of family and/or current placement links
- reducing numbers of hospital re-admissions
- facilitating time out of home without using a hospital place
- fewer obstacles to communication because of closer geographical base
- review assessment and alteration of medication through local psychiatry input
- less traumatic experience for the individual
- more appropriate targeting to meet specific needs
- more person centred approach
- greater continuity/stronger links to local learning disability supports
- better use of acute scarce resource
- local services encourage care and resolution to the individual's difficulties
- effective and co-ordinated liaison and integration with other local services. **(Recommendation 47)**

8.21 As a consequence of the development of community based assessment and treatment services, admission to specialist hospitals solely for people with a learning disability will become increasingly less frequent. DHSSPS should commit to reviewing and evaluating the developing community services and the need for continuing specialist hospital provision. Ultimately it is hoped that there may not be a need for specialist hospitals for assessment and treatment solely of those with a learning disability.

8.22 In order to enable community provision to develop there is a need for clarity about the shift in resources and the additional funding that will be required. This should be agreed at a regional level in order to avoid perpetuation of service inequities and to address the complex issues involved in commissioning this level of specialist provision. This should take account of the training requirements for the recognition of mental health and challenging behaviour problems across the whole range of people providing care and support. **(Recommendation 48)**

8.23 A small number of people with a learning disability have severe challenging behaviour or mental illness that is liable to relapse. Staff and carers must be alert to warning signs of a recurrence and share information about such signs. To encourage better liaison and clarity of roles and responsibilities between specialist and community services in relation to such people, Health and Social Services Trusts should ensure that protocols are agreed for proactive approaches to intervene in a systematic way should there be warning signs of recurrence. **(Recommendation 49)**

8.24 There is a significant level of concern raised by staff about the lack of guidance on the appropriate management of challenging behaviours and the complex legal, human rights and practical issues involved. It is recommended that a regional approach be adopted to developing clear guidance in this area for all learning disability services in Northern Ireland. Similar initiatives in England have assisted in providing a framework in which both people with a learning disability and their carers can be supported and the required training strategies developed. **(Recommendation 50)**

8.25 Objective 7 Recommendations

Recommendation 45	As a matter of urgency the Department of Health, Social Services and Public Safety should consult with all 4 Health and Social Services Boards about their present and future plans for specialist assessment and treatment services for men and women with a severe learning disability with a view to greater sharing of existing and planned resources and the development of new forms of community based services.
Recommendation 46	By the end of the Review period people with high levels of adaptive functioning/mild learning disability who require therapeutic intervention as a result of mental health problems should be able to access mainstream mental health services. Support from dedicated learning disability services should be available if required.
Recommendation 47	Community based assessment and treatment services should be developed on an incremental basis to provide assessment and treatment of men and women with a learning disability who have specific mental health needs and/or challenging behaviours. The community based assessment and treatment services will encompass behaviour support expertise that will provide outreach to individuals, families and community services and short-term intensive treatment to those within a residential facility which may be approved to treat people under mental health legislation.
Recommendation 48	As a consequence of the other mechanisms being recommended the Department of Health, Social Services and Public Safety should establish a regional plan that sets targets for the reallocation of existing resources and the securing of additional resources to enable the community services to be established.
Recommendation 49	Some people with a learning disability are at increased risk of recurrent severe challenging behaviours and/or mental illness. Health and Social Services Trusts should ensure that protocols are agreed so that a proactive approach can be taken to systematic intervention should there be signs of recurrence.

Recommendation 50 By December 2006 the Department of Health, Social Services and Public Safety should produce in partnership with service providers regional guidelines on the management of challenging behaviours within services.

GROWING OLDER

Chapter 9

“ ”

One of the great social achievements of the 20th century has been increased longevity of people with learning disabilities due to advances in medical care and social support. (137)

9.1 The life expectancy and number of older people is increasing across most developed countries. Most people with a learning disability who survive beyond 30 years will have average life expectancy and experience normal ageing processes. Many will experience a long and healthy old age. Growing older is also likely to include a number of additional challenges for people with a learning disability owing to the impact of their disability. The Equal Lives Review found limited evidence of strategic planning, specific policy or changing practices that will meet the emerging needs associated with increased numbers and needs of older men and women with a learning disability or their family carers in Northern Ireland.

Objective 8 To ensure that men and women with a learning disability are supported to age well in their neighbourhoods.

Issues and Concerns

Difficulty in Definition

9.2 Old age is a relative concept, the definition of which is affected by social, psychological and biological factors. Therefore, being old might be defined by social benchmarks such as retirement age, physical signs of ageing, or the degree to which one feels old.

9.3 Men and women who have a learning disability may experience each of these quite differently. The degree to which many men and women with a learning disability have been excluded from the social opportunities and life chances available to others means that society’s benchmarks may be applied less satisfactorily, as typified by the question posed to us by a man with a learning disability at a meeting, *Am I ever going to be allowed to retire from my day centre?* The physical signs of ageing may affect some people with a learning disability at an earlier age. (50) There is limited evidence on how well men and women with a learning disability cope psychologically with ageing. It could be that due to cognitive limitations some people find difficulty understanding the ageing process. This may be worsened by the fact that many individuals with a learning disability are prevented from experiencing normal life events e.g. they may be hindered in the acceptance of mortality, as they are frequently not exposed to rituals such as funerals in an attempt to protect them from unpleasant events. (49)

9.4 Owing to these factors and the potential additional supports that may be required, it has been proposed that planning to meet the ageing needs of men and women with a learning disability should begin at an earlier stage and no later than 50 years.

Impact of Ageing

9.5 As noted there may be significant differences in the impact of ageing for men and women with a learning disability as compared with other people in Northern Ireland.

- A number of different types of dementia exist, but the most significant and prevalent is Alzheimer's Disease. The neurological effects of this disorder are devastating for the person who develops it and for his/her family. It leads to deterioration in function in virtually all aspects of life, a disintegration of the affected person's personality and eventually death. Research evidence indicates that people with Down's Syndrome show neurological changes resulting from Alzheimer's type dementia at a much younger age than others, and in addition virtually all people with Down's Syndrome who live long enough will develop this type of dementia. (138)

Table 3: Percentage of people with Down's Syndrome affected with Alzheimer's Disease (139)

Age in years	Rate %
30-39	0-10%
40-49	10-30%
50-59	20-55%
60-69	30-75%

- Men and women with a learning disability may also develop what are known as syndrome-specific conditions including congenital heart defects/visual and hearing disorders (Down's), musculo - skeletal problems (Fragile-X) and obesity related diabetes (Prader-Willi). (138, 140-144)

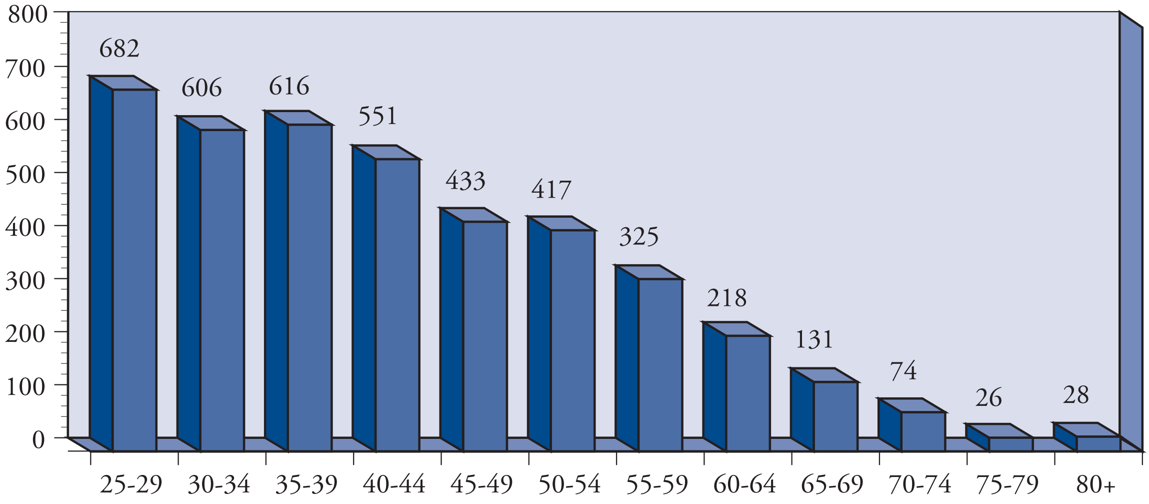
9.6 Between 20-40% of older men and women with a learning disability are liable to have a mental health problem. (145)

Numbers

9.7 There is clear evidence of the increased numbers of older men and women with a learning disability in Northern Ireland.

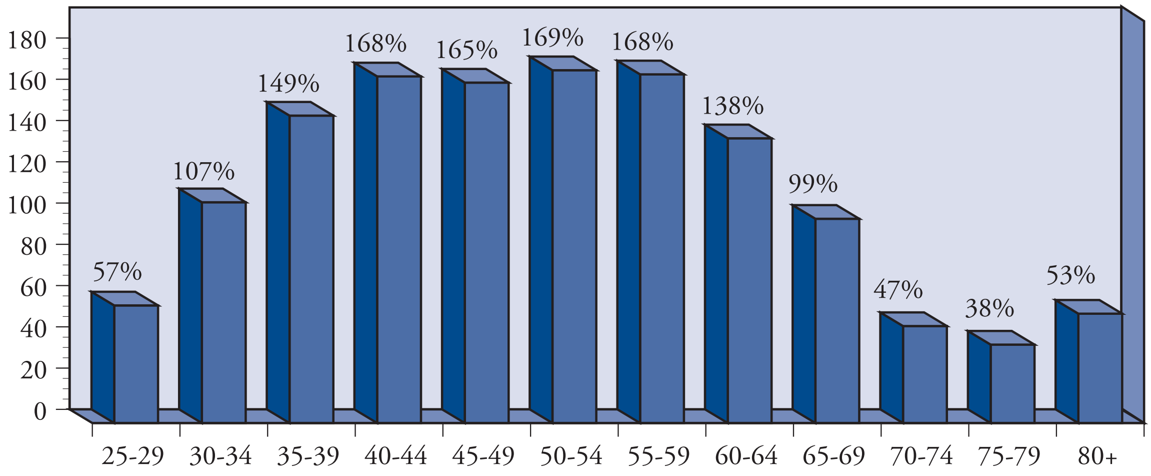
- The prevalence study of people with a learning disability in Northern Ireland (15) identified that out of 4,107 people with a learning disability living in ordinary homes 477 (12%) are aged over 60 years of age (Figure 7). If we applied the definition of old age as starting at 50, then 1219 (30%) people could be considered to fall within the older adult population.

Figure 7: **The number of people living in community settings (i.e. with family carers; own accommodation) in 5-year age bands. (N=4107) (15)**



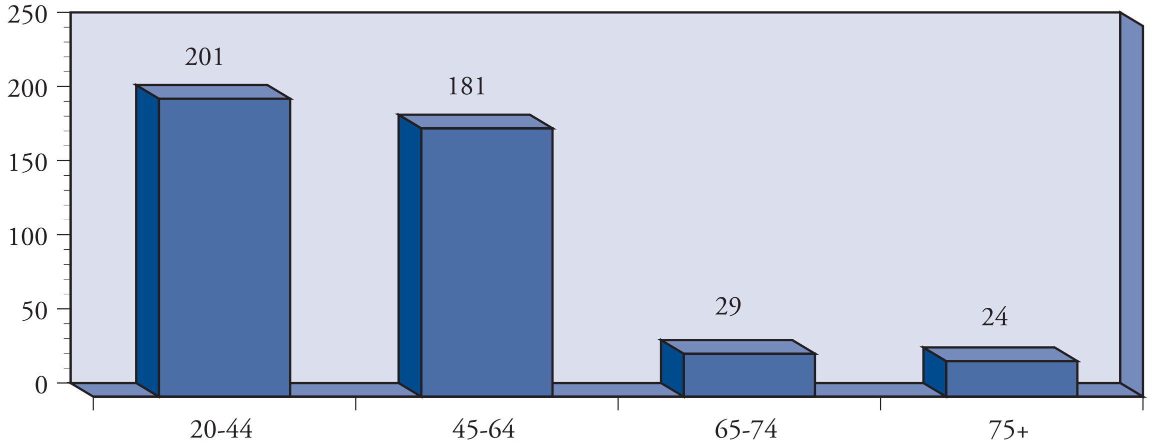
- This study also identified the number of people with a learning disability living in residential or supported living. These figures show that of 1,358 people in supported/residential living, 375 (28%) were over 60 years of age and 712 (52%) were aged over 50. (Figure 8)

Figure 8: **The number of people living in residential and supported living settings in 5-year age bands (N=1358) (15)**



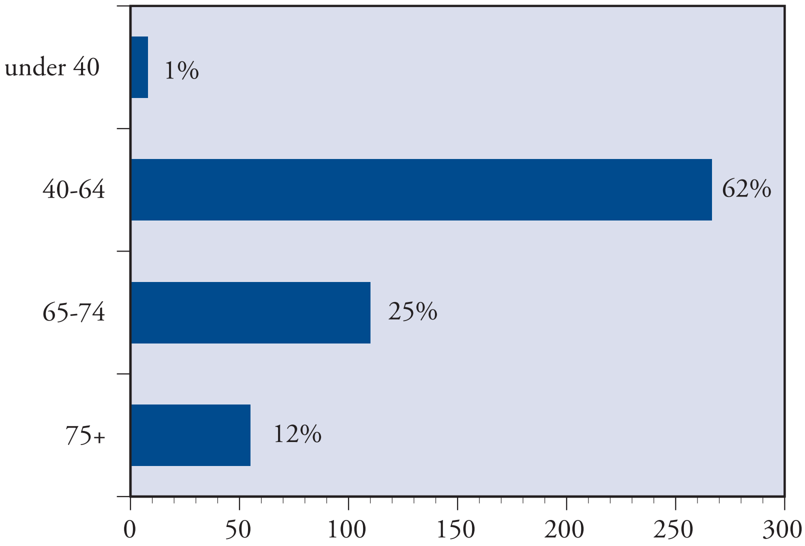
- Of the 435 men and women with a learning disability who had been in a hospital for more than one year, 53 (12%) were aged 65 years and over and over half of the hospital residents (234, 54%) were aged 45 years and older. (Figure 9)

Figure 9: The number of in-patients in hospitals greater than 366 days in age bands (N=435) (15)



- In another study in Northern Ireland that investigated future housing needs in one Board area, 37% of family carers were over 65 years old. The report author projects this to the other data presented and estimates that nearly 500 men and women with a learning disability live with a carer aged over 75 years, and a further 1,000 people live with a carer aged over 65 years.

Figure 10: The number and percentage of primary carers by age bands looking after people with a learning disability aged 25 years and over in EHSSB area (N=436) (99)



Family Carers

> *Over the last few months I have been to three funerals of adults with a learning disability. Each time I hugged the mother and told her now you can let go. Parents worry so much what will happen to their children after they die that they pray that their son or daughter dies first so they will not be left to fend for themselves.* (2)

9.8 Family members continue to provide the bulk of caring as men and women with a learning disability grow older. For many this can be a positive experience and a preferred choice over other options because of a number of factors:

- parents self-select to care for their son/daughter rather than having them placed in care
- after many years of caring parents adjust and accommodate to the caring role
- parents build a long-term relationship with their son/daughter and do in fact gain and feel they have a purpose in life fulfilling the caring role. (146, 147)

9.9 However, there are a range of issues relating to the role of family carers as they and their relative get older including:

- older family carers are under greater physical and mental pressures because of their age and the frailty this often brings; and as they age, they become increasingly anxious about the future
- because of the duration of the caring relationship, which is often life-long, they are likely to have a particularly intense, interdependent relationship with the person they are supporting
- they are more likely to be caring alone
- they have smaller support networks as parents, partners and friends age and die
- they have a very different experience of the service sector from new generations of carers. They were often advised to forget or reject their child, encouraged to have very limited expectations of his or her life expectancy or abilities and usually had to fight very hard for any support from the statutory sector.
- older family carers are often very reluctant to seek help. Reasons for this include past negative experiences of the paid service sector, and a fear that by seeking help they are admitting their own diminishing capacity and that they will lose control. (146)

9.10 Similar issues have been described in the limited research in Northern Ireland on the experiences of older people with a learning disability or their carers e.g. one study in a Health and Social Services Trust found that:

- deterioration in mobility of their ageing relative was the most common problem reported by family carers followed by the onset of epilepsy, reported by 45% and 33% of carers respectively
- most of their support came from social workers and GPs but rarely more than a visit once every 6 months to one year. (147)

9.11 Despite the fact that family carers are entitled to a separate assessment of their needs we found that there was a very limited awareness or uptake of this amongst family carers in Northern Ireland. (2)

Futures Planning

9.12 During the consultation for the Equal Lives Review family carers frequently raised their concerns about the future and a wish for workers to support them to make plans for when they may no longer be able to meet the care needs. However, they noted how difficult this was and that on occasions an apparent refusal to look towards the future was a reflection of the pain involved in contemplating their own mortality and the consequences for their son or daughter. (2) Carers were particularly concerned that futures planning should address issues of capacity and consent, to ensure that this responsibility was appropriately placed in the absence of the main carer. There are few precedents for older people with a learning disability remaining in the family home in the absence of the main carer. This offers considerable scope for extending the range of housing options available to older men and women with a learning disability.

9.13 There has been a serious dearth of service planning to meet the future needs of men and women with a learning disability as they age. This is reflected in the very limited local research, absence of a departmental steer on expectations of services to develop appropriate responses, confusion about the interlinking roles of learning disability, older people and dementia services and an apparent failure to recognise the potential pressures arising from the increased numbers and needs on future service provision. One result has been that older men and women with a learning disability are being moved from their accommodation, and often their familiar day supports, at extremely vulnerable periods in their lives.

Ageing Well

9.14 In contrast with developments for older people generally there has been little emphasis on health and well being for people with a learning disability. Ageing well has not been actively encouraged or supported by services to date. The consequences of this are now becoming evident in our population of older people with a learning disability.

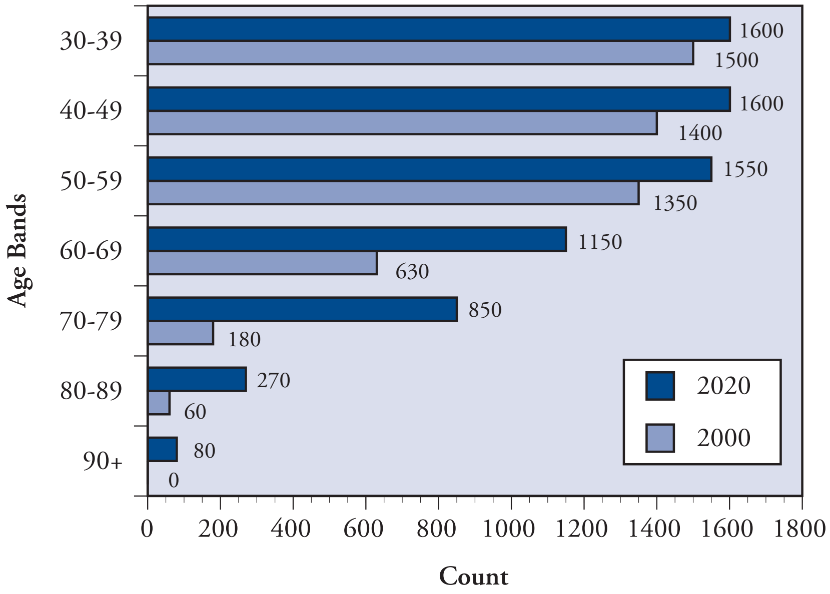
- Older men and women with a learning disability have few opportunities to take part in leisure pursuits. (148) This is due to the health problems they face, perceptions of them as a lower social status group, exclusion rather than inclusion within their community and lack of support to access leisure activities. (149)

- In line with the general population, issues around diet and exercise are coming to the fore and are generally exacerbated for people with a learning disability due to many factors, not least their poor access to primary care services. (150, 151, 152)

Action Required

9.15 Over the next 15 years using predictions for the wider population, we estimate that the number of men and women with a learning disability in contact with health and social services who are aged over 50 years will rise from around 2,200 in 2000 to 3,900 as Figure 11 shows; a predicted increase of 81%. The figure of 3,900 represents around 0.58% of the predicted population of people aged over 50 in 2020 (672,000) and 1.23% of the predicted population aged 65 years and over (319,000).

Figure 11: Projected increase in the number of people with a learning disability from 2000 to 2020.



9.16 In order to remedy the serious lack of strategic planning to address the particular issues associated with ageing there is an urgent need for focused planning and reconfiguration of service delivery in this area.

9.17 As the ageing process for some men and women with a learning disability may begin much earlier, planning for them should begin much earlier. Planning for those people aged 50+ should be prioritised immediately, and should be developed in conjunction with people with a learning disability. As PCP is progressed with all people, planning for the future will naturally happen from an earlier age. We suggest that it includes those aged 50 and upward, which would mean that:

- monitoring would allow early identification of potential problems and thus improved planning to meet this growing need
- potential crisis management could be avoided especially following the death of a sole carer
- service user and family education and preparation for growing old could be planned for earlier and therefore be more effective.

9.18 Redefining ageing in this manner would necessitate revised arrangements for the allocation of resources to meet the needs of this group. In particular the interface between funding for elderly services and that for learning disability services would need to be reviewed and more flexible connections between both programmes facilitated. (Recommendation 51)

9.19 An ageing in place culture should be facilitated by support services if, through PCP, men and women with a learning disability and family carers reveal that this is their preferred option. Research indicates that this is most likely to be the case and is certainly the most cost-beneficial option for HPSS services. This raises fundamental questions about the most appropriate service model(s) to meet the needs of both family carers and older people with a learning disability.

> *We are not sure whether we should be valuing our elderly clients by regarding them as people with unique needs or valuing them by treating them no differently from anyone else.* Moss (152)

9.20 There are potentially a number of models that might be developed including:

- developing expertise within learning disability services to enable them to meet the needs associated with ageing
- ensuring that older men and women with a learning disability can access supports from services for older people and possibly before 65 years of age
- developing clear linkages between specialist learning disability services and older people's services to ensure that skills are shared between both groups but facilitating greater choice by men and women with a learning disability so that they can age in place if desired.

9.21 Applying the Equal Lives Values and in particular the requirement to individualise support planning, it is evident that within future provision there may be a need for not one, but several models. Clearly this would require greater cross-programme and multi-disciplinary co-operation. There will also be a need for a more flexible approach to resource allocation to meet the joint needs of both the individual and their elderly family carer. The interdependence of both must be recognised.

9.22 Given the absence of coherent work in Northern Ireland to address these issues we believe that a regional approach should be adopted to develop clarity about the strategic direction to be taken and the changes to organisational structures and systems that should ensue. This work should be led by the Department of Health, Social Services and Public Safety and involve the development of a regional network wherein knowledge and expertise about ageing issues might be further researched, shared and developed. The outcome should be a regional framework that addresses at least the following:

- values and principles derived from the Equal Lives values as they apply to the ageing population of people with a learning disability
- information audit of need
- creation of a policy framework
- development of local partnerships between learning disability services and the elderly programme of care
- human resource implications in both of the above sectors
- strategy for optimising health
- involving older people with a learning disability in decision-making
- promoting positive lifestyles for older men and women with a learning disability through voluntary and community organisations
- forward planning[8]. **(Recommendation 52)**

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[8] Adapted from the checklist for action in Preparing for a Positive Future (153)

9.23 There is a need for a complementary process to be undertaken to address the issues for men and women with a learning disability who develop dementia including those who are younger. These issues are currently under consideration by the Expert Working Committee on Dementia and Mental Health Issues in Older People of the overall Review. We recommend that the framework that is developed ensure that men and women with a learning disability who develop dementia should be enabled to access support and expertise from mainstream dementia services in their locality. This will require close cooperation between learning disability specialists and those who have expertise in dementia. **(Recommendation 53)**

9.24 Objective 8	**Recommendations**
Recommendation 51	The Department of Health, Social Services and Public Safety should review funding allocations to ensure that the projected increase in numbers of older people with a learning disability is reflected in the allocations to the learning disability programme. This shift will take cognisance of the fact that people with a learning disability may experience the effects of ageing at an earlier age.
Recommendation 52	The Department of Health, Social Services and Public Safety and Health and Social Services Boards should produce a strategic plan to address current deficiencies in services and future service provision for older people with a learning disability and their families.
Recommendation 53	Arrangements should be developed to enable people with a learning disability who have dementia to access support and expertise from mainstream dementia services. This will include mechanisms to provide a skills boost between dementia services and dedicated learning disability services.

ENSURING PERSONAL OUTCOMES

Chapter 10

> *We hope that the Review will make sure that there are more advocacy groups and more chances for people to speak out and be listened to. We do not think this happens enough and that is why things go wrong.* (1)

10.1 The Equal Lives Review has concluded that progress needs to be accelerated on establishing a new service model, which draws a line under outdated notions of grouping people with a learning disability together and their segregation in services where they are required to lead separate lives from their neighbours. The model of the future needs to be based on integration, where people participate fully in the lives of their communities and are supported to individually access the full range of opportunities that are open to everyone else. This will involve:

- developing responses that are person centred and individually tailored
- ensuring that people have greater choice and more control over their lives
- services becoming more focused on the achievement of personal outcomes, i.e., the outcomes that the individuals themselves think are important
- increased flexibility in how resources are used
- balancing reasonable risk taking and individuals having greater control over their lives with an agency's accountability for health and safety concerns and protection from abuse.

10.2 In this chapter we will outline the issues that support or impede this direction of travel and the specific actions that are required to achieve it.

Objective 9 To enable people with a learning disability to have as much control as possible over their lives through developing person centred approaches in all services and ensuring wider access to advocacy and Direct Payments.

Issues and Concerns

Person Centred Approaches

10.3 Throughout the Equal Lives Review process it was evident that many services in Northern Ireland are seeking to develop a greater focus on meeting individual needs and aspirations through person centred approaches to planning and support.

10.4 However, PCP appears to have been the result of determination on the part of individuals or groups within services to transform working methods rather than a consequence of a shift in strategic direction within organisations. Therefore, as in other areas of practice, the likelihood of being offered the opportunity to participate in a PCP process depends more on where you live rather than on the degree to which you might benefit. (1)

10.5 There is some confusion about the terms in use, which we seek to clarify here.

PERSON CENTRED APPROACHES

…ways of commissioning, planning, and organising services that are based on listening actively to what people want and tailoring services to individual needs rather than fitting people into available services.

PERSON CENTRED PLANNING (PCP)

…a process for continual listening and learning focusing on what is important to someone now and in the future and acting on this in alliance with their family and friends. (154)

PERSONAL OUTCOMES

…the effects of an intervention that focus on the issues that matter most to people in their lives and checking to ensure that they are being met.

10.6 Developing a person centred approach within existing service agencies will require cultural and organisational changes and fundamental shifts in the ways in which decisions are taken and implemented.

10.7 Throughout the Equal Lives Review people expressed considerable support for PCP to be made available to all people with a learning disability. This support was voiced at presentations to the Learning Disability Committee, at meetings with the Equal Lives Group and carers and by each of the 6 Task Groups. Future energies will need to focus on ensuring that where person centred plans are developed, sufficient attention is given to their implementation to ensure that they result in better outcomes for the individual.

Direct Payments

10.8 The Carers and Direct Payments Act (NI) 2002 makes provision for people to have increased control over the services they receive and for carers to have their needs recognised formally. The Act:

- requires Health and Social Services Trusts to inform carers of their right to an assessment
- gives carers a statutory right to assessment of his/her ability to provide and continue to provide care for the person cared for
- places a duty on Trusts to supply services that meet the personal needs of carers as well as the person they care for
- enables carers to purchase, through a Direct Payment, the services they require to meet their own assessed needs.

10.9 There was a low level of awareness about these provisions amongst the carers who attended the Equal Lives Review meetings. Concern was also expressed about the length of time taken to complete these procedures and the level of support that was offered as a result. (2)

10.10 The Community Care Direct Payments Act (1996) made it possible for disabled people, including those with a learning disability, to have a Direct Payment from Health and Social Services Trusts to pay for their community care services. The individual can use the money to buy or organise the kind of support that best suits them rather than use services provided by Trusts or other organisations on their behalf. There has to date been a very low uptake of Direct Payments by people with a learning disability in particular but also among others with a disability. At March 2004, out of 107 people in receipt of Direct Payments in Northern Ireland, 12 had a learning disability. (155) The Belfast Centre for Independent Living has established an advice and support service in Direct Payments which to date has had limited requests from people with a learning disability or their family carers.

Advocacy and Information

10.11 Current Government policy stresses the importance of people being able to have a say about how services are run and for services to be more user-led. Yet many people with a learning disability find it hard to make their voices heard. Advocacy can help people let others know what is important to them and have influence over decisions, which affect them.

10.12 Compared with England, Scotland and Wales, the range and volume of advocacy services for people with a learning disability in Northern Ireland is low. There are examples of good practice throughout Northern Ireland, but these are sporadic and often groups are relying on unpredictable funding and volunteer support to keep them going. Very few people that we met during the Equal

Lives Review meetings had access to an independent advocate or to opportunities for support in self-advocacy. (1) There is no regional forum of people with a learning disability.

10.13 Between 50% and 90% of people with a learning disability have some communication difficulties (depending on the definitions used and the survey population). Four out of 5 people with severe/profound learning disabilities have no effective speech, although they will demonstrate what they want to communicate by other means. (156) This places an onus on agencies to ensure that people with a learning disability are informed about issues that will affect them in a way that takes account of their communication needs. Agencies also need to hear what people say and adapt their processes to ensure that people are listened to.

Quality

10.14 As noted above the benefits of PCP were regularly highlighted to us during the Equal Lives Review. However, we are concerned to ensure that PCP is not viewed as an end in itself. Rather it is the first step in the process of ensuring that people with a learning disability and family carers achieve personal outcomes through their involvement with support services. To us this is the core definition of a quality service.

10.15 Key drivers for measuring and assuring that this happens are the commissioning processes of funders and the monitoring of standards by regulators. There are currently no agreed systems for assessing the quality of life and personal outcomes for people with a learning disability across the full range of services on offer to them. Much current regulation of residential and nursing homes focuses on issues of physical structure and process rather than on measuring the impact on people's lives through determining what the individual regards as important. Growing emphasis on health and safety legislation has created further pressures to institutionalize services in order to meet stringent standards.

10.16 The Government is engaged in a series of initiatives that are designed to improve quality in services. A key element of this is the establishment of the Health and Personal Social Services Regulation and Improvements Authority (HPSSRIA), which will inspect care services against a set of national care standards. This development has the potential to support the increasing emphasis that we feel is needed in all services for people with a learning disability on personal outcomes. However, a number of people who contributed to the Equal Lives Review raised concern that unless the care standards are based around promoting person centeredness in services the opportunity for them to support the inclusion and individualised aspirations of service beneficiaries will be lost. More worryingly, this development will run counter to the values underpinning the Equal Lives Review.

10.17 This emphasis on personal outcomes is equally applicable in specialist assessment and treatment services relating to a person's physical and mental health, or their challenging behaviour. It is imperative that the contribution of these services is closely aligned to the broader PCP for the person.

Research and Information Needs

10.18 In order to raise the quality of supports it is necessary to have a sound evidence base on which to base recommendations for change, development or maintaining existing practices. As part of the Equal Lives Review an audit of learning disability research was commissioned and disseminated on the Review website. This audit highlighted the value of such concrete links between research and policy formulation and practice. It also raised a number of issues that need to be considered in ensuring that the implementation of the Equal Lives Review's recommendations is supported by a coherent research strategy. Further research on the assessment of personal outcomes and the impact of person centred planning should be a key area for research and development during the first 5 years of the implementation of the Equal Lives Review.

10.19 We have highlighted the deficiencies that exist related to information and research on issues relevant to learning disability. The audit of learning disability research undertaken for the Equal Lives Review has identified key research findings that service providers and commissioners need to address along with the significant gaps in our knowledge. The list below is not exhaustive, but is included to highlight the significant gaps that exist in terms of meeting the change agenda detailed in the Equal Lives Review:

- the socio-educational outcomes for children, families and schools when pupils with a learning disability attend mainstream schools compared to special schools
- meeting the personal support needs of family carers at different stages of their son or daughter's life cycle - new born; transition to adulthood; maturity - and as they, as parents, approach old age
- the benefits systems and the impact on poverty in families and people with a learning disability
- tracking young people through different transition routes to understand better the outcomes of various options open to them - college, employment, and day centre attendance
- evaluating ways of increasing the social connectedness of teenagers and adults with a learning disability
- the contribution of productive work - paid and unpaid - in the lives of people with a learning disability
- exploring the obstacles to self-advocacy and how they are best overcome
- ensuring equality of access to healthcare in all its forms for people with a learning disability
- reducing obesity among people with a learning disability
- establishing the outcomes of various accommodation and support options for people with a learning disability, who also have challenging behaviours/mental health problems
- supporting people with a learning disability who have dementia in community settings
- promoting the engagement of volunteer helpers in learning disability services
- evaluating the role of community development agencies in promoting the social inclusion of people with a learning disability.

Action Required

10.20 In order to ensure that people with a learning disability and their family carers have a greater say in decisions that affect them and to support the development of more person centred approaches, there is a need for radical shifts in how organisations operate and opportunities available for participation and influence. We will develop this theme further in Chapter 12.

10.21 The cornerstone of this work will be embedding PCP throughout services and ensuring that all those individuals in contact with health and social services are enabled to have a PCP developed with them if they so choose. This plan will be co-ordinated by the lead worker from the agency that is identified by the person and their support staff as being best placed to do so and the PCP would be held by the individual but shared with their permission with all agencies and personnel involved with the individual.

10.22 At various stages in the Equal Lives Review we have proposed that PCP is particularly important at the point of discovering that a child has a learning disability, in preparing for the transition to adulthood, and in enabling people to plan for the future as they get older. In addition priority should be given to developing a PCP with individuals with complex needs including those who may have particular difficulties in communicating their needs and aspirations as a result of having an Autistic Spectrum Disorder or severe learning disability. Achieving this will require organisations to work collaboratively and to undertake reviews to their current practices especially to enable the shift in attitude and culture that effective PCP requires. **(Recommendation 54)**

10.23 Direct Payments have the potential to be highly effective in giving people control over their lives. Supporting people to purchase the support they need to fit their own unique circumstances should be a key driver towards helping them achieve personal outcomes. Even a modest increase in the uptake of Direct Payments by people with a learning disability and family carers of 10% per annum over the next 15 years would result in around 1,000 beneficiaries (Based on people aged over 20 and children with severe/profound disabilities). There is clearly a need to more widely promote this option and to create more flexible resource allocation to enable it to be taken up by those who wish to do so. However, all these costs could not be met from within existing HPSS budgets as only a small proportion of present funding is spent on variable costs. Thus in England, the Department of Health announced an additional £9million over 3 years to boost Direct Payments for people with a learning disability. A similar initiative is required in Northern Ireland in order to support the uptake of Direct Payments. **(Recommendation 55)**

10.24 In order to ensure that people are supported to have their views heard and acted upon there is a need to address the underdevelopment of independent advocacy services in Northern Ireland. Advocacy can take many forms including group advocacy, self-advocacy and citizen advocacy. In all cases advocacy services should fulfil 3 roles: educational - raising awareness about the strengths, needs and aspirations of people with a learning disability within the community at large; bringing about change to the way that systems work with individuals; and creating collaborative links between people with a learning disability and other groups/organisations in the wider community. The extension in range and volume of advocacy services should be a key priority for planners in the future if more person centred outcomes are to be attained. The development of advocacy services will also facilitate the establishment of a Regional Forum of People with a Learning Disability that we believe is an integral component of implementation arrangements for the Equal Lives Review. **(Recommendation 56)**

10.25 In Chapter 4 we recommended that steps be taken to address the gaps that exist in ensuring that information is available that meets the needs of people with a learning disability and their families. We believe that in addition to this specific measure there is a need to encourage all those who provide services to people with a learning disability to take steps to ensure that they produce information in accessible ways that are tailored to meet the needs of the specific individuals with whom they work. **(Recommendation 57)**

10.26 In order to ensure that the Government's drive to improve quality is meaningful there is a need to develop measures that address the effectiveness of organisations in delivering personal outcomes. This will mean that systems have to be more responsive to the fact that desired outcomes of support are highly individualised and that the focus needs to be on the issues that matter most to the individual who is being supported. If standards are developed that effectively measure personal outcomes in this way, regulators and service commissioners will have a key role to play in promoting person centeredness in services with correspondingly less emphasis on setting standards to be applied uniformly across a diversity of service responses. **(Recommendations 58, 59)**

10.27 It is proposed that the research requirements identified are addressed through the development of an agreed learning disability research strategy, which will encompass the following elements:

- development of links between Northern Ireland researchers and other national and international researchers in learning disability in order to access more research funding
- consideration of the uptake of existing research findings and their use in decision-making
- the participation of stakeholders in deciding on research questions
- the development of researcher-practitioners
- boosting the amount of resources available for research and development within Northern Ireland
- instigating and managing cross-national research projects.

10.28 In conducting the Equal Lives Review we have highlighted difficulties in accessing accurate information on the numbers, needs and services available to people with a learning disability and on the amounts of funding being invested in services for them. In order to accurately evaluate the impact of the implementation of the Equal Lives Review recommendations and to plan more effectively there is a need to establish better systems for tracking people and funding and assessing outcomes. In particular new systems should provide information on services and supports needed by individuals as well as those they are receiving. These records should allow for better integration of information that to date is held separately in education, health, social services or housing systems, taking account of the Data Protection Act. Experiences in England, Scotland and Republic of Ireland would help to inform the development of an appropriate data set. **(Recommendation 60)**

10.29 Objective 9 Recommendations

Recommendation 54 By 1 January 2009 the opportunity to have a PCP should be in place for all persons with a learning disability who are in contact with HPSS agencies. From 2006 priority should be given to:

- developing Family Support Plans based on person centred principles that cross disciplines and agencies
- developing an Early Intervention Plan for children at the point of diagnosis
- ensuring that all young people with a learning disability have an effective Transitions Plan based on PCP principles in place from 14 years of age
- ensuring that all persons living with a sole family carer and/or those aged over 50 years have been offered the opportunity to have a Futures Plan agreed based on PCP principles. In addition a plan for meeting the needs of carers should be prepared. This invitation should be re-issued to family carers and the person they care for on a regular basis and no less than every 3 years.

Recommendation 55 The use of Direct Payments should be widely promoted and additional revenue monies of up to £300,000 per annum over the next 3 years ear-marked by the Department of Health, Social Services and Public Safety for the development of increased uptake of Direct Payments.

Recommendation 56 An independent advocacy service should be in place for each area serving a population of 100,000 - 120,000. A Regional Forum for People with a Learning Disability should be established with representatives drawn from local advocacy services. Both initiatives should be grant-aided through Office of the First Minister and Deputy First Minister (OFMDFM), so that they can cover all services and not just those provided by the Department of Health, Social Services and Public Safety.

Recommendation 57 A commissioning requirement of any service that includes people with a learning disability must be the evidence from providers across departments and agencies of how information will be provided in an accessible format appropriate to the needs of the individuals being supported.

Recommendation 58 Health and Social Services Boards should be required, within a regionally agreed framework, to establish mechanisms in partnership with their service providers for monitoring the degree to which Person Centred Planning is appropriately implemented and delivers on positive personal outcomes for individuals with a learning disability.

Recommendation 59 The Health and Personal Social Services Regulation and Improvement Authority should include measurement in the standards against which learning disability services are inspected of the processes used in service delivery to secure positive personal outcomes.

Recommendation 60 A commissioned programme of research and service evaluation to support the implementation of the Equal Lives Review should be established in collaboration with the Research and Development Office.

ENABLING CHANGE: STAFFING

Chapter 11

“ ”

> *All staff who work with people with a learning disability should get special training so that they understand how to respect people and know what to do to support people with a learning disability.* (1)

11.1 The biggest single contributor to quality services is the competence of the staff, both paid and unpaid, who are employed in them. Throughout the Equal Lives Review we have heard how people’s lives have been enhanced by the relationships they have formed and the support they have received from the staff with whom they have come in contact. Since the last review of policy in 1995 there have been considerable changes that impact on developing a competent workforce in health and social care services:

- the volume and range of services has expanded creating a need for an extension to the workforce within and beyond health and social services
- an increase in the input of Direct Support Workers and an expanded range of roles that they undertake
- an increase in the numbers of Direct Support Workers employed on a part-time basis
- new or increasing demands arising from the changing demography and complex needs of people with a learning disability including:
    - addressing issues associated with working with an ageing population
    - increasing numbers of people with both an Autistic Spectrum Disorder and a learning disability
    - growth in number of children and adults who have complex physical health care needs.

11.2 Consultation conducted as part of the Equal Lives Review highlighted a range of positive characteristics in relation to developments in the workforce in response to these changes.

- Staff are increasingly developing approaches based on working with rather than for people with a learning disability and their families.
- There is now a higher profile for learning disability services, which has contributed to raising the confidence and status of staff in these services.
- The new and changing roles have created new opportunities for staff and have in many cases resulted in innovative service responses to staff training and development.

- The introduction of the Learning Disability Awards Framework (LDAF) has offered a coherent learning pathway for many Direct Support Workers in residential and day services in the WHSSB and in a growing number of voluntary agencies in Northern Ireland.

- Many individuals reported that there has been skills improvement amongst staff in learning disability services and an increased focus on their training.

11.3 The availability and retention of an appropriate range of qualified and competent staff will be crucial to the successful implementation of the Equal Lives Review. In this chapter we will explore the key factors that will impact on achieving this and outline our recommendations on the action required to build on the significant strengths that are currently in place amongst those who work with people with a learning disability and their families.

Objective 10 To ensure that health and social care staff are confident and competent in working with people with a learning disability.

Objective 11 To ensure that staff in other settings develop their understanding and awareness of learning disability issues and the implications for their services.

Issues and Concerns

User Involvement

11.4 Potentially one of the most powerful ways of raising awareness of the needs and aspirations of people with a learning disability and their family carers is to ensure their involvement in staff recruitment and development.

- During the Equal Lives Review we learned of a number of initiatives in this area, albeit that they are occurring in isolation from broader workforce strategies.

- Our understanding of the issues was greatly informed by the many presentations we heard from people with a learning disability and family members.

- This is an area that should be promoted more widely in agencies.

Recruitment and Retention

11.5 The recruitment and retention of staff is a key challenge for services both in Northern Ireland and throughout the United Kingdom.

- There is a lack of accurate data on either the current workforce or future workforce requirements on which to effectively develop strategies to address recruitment and retention difficulties.

- Staff in existing learning disability hospitals will have an important role to play within community based settings as the number of people living in hospitals reduce.

- Whilst several professional groups have published their standards for staffing levels in relation to the population size covered, limited information appears to be published in relation to the current level of recruitment among the different professional groups and the present level of unfilled posts. However, there appears to be a general consensus that recruitment of Allied Health Professionals - notably speech and language therapists - is difficult in Northern Ireland at present. This may be because they are able to work in a wide range of settings and learning disability may not be presented as an attractive career pathway. Similarly difficulties appear to exist in recruiting staff to clinical psychology posts. Applications to learning disability nurse training have been reducing and by tradition there have always been fewer recruits to this branch of the profession.

- No clear and concise information is currently compiled at a Northern Ireland level on the difficulties being experienced in recruiting qualified and unqualified staff into statutory or independent learning disability services and the factors thought to be contributing to these difficulties.

- There are clear benefits in achieving a cohesive and experienced staff group. These include increased continuity within services; a growth in staff skills and knowledge with experience and it offers a greater return on the investment in training and reduced costs of recruitment. (157)

- The most comprehensive review of literature relating to the retention of staff within community based services for people with a learning disability within the United Kingdom and the USA identified 8 key factors that have been consistently reported as contributing to staff turnover in learning disability services. (158) These factors were:

  - characteristics of staff (younger people, those with higher education and those on shorter contracts moved on more frequently)
  - lower income/less satisfaction with income
  - mismatch between expectations and actual job
  - lack of commitment to the organisation or general type of work
  - lack of support from other staff
  - the availability of alternative employment
  - high job stress
  - low job satisfaction.

11.6 A wide range of factors have been highlighted that contribute to staff remaining in services, awareness of which can inform the development of a strategy to address retention difficulties. Key factors include effective stress management in the workplace, enabling a good work/life balance, effective support from managers and clarity about roles and responsibilities. (157, 158)

Volunteers

11.7 A much-neglected area of study is the role that unpaid volunteers play in supporting people with a learning disability.

- The invaluable contribution made by family carers who still provide the vast majority of support has been highlighted throughout the Equal Lives Review. Although it is impossible to accurately assess this financially, when it has been done for all carers in Northern Ireland (159) and then pro rated for those likely to be caring for a child or adult with a learning disability, the total amount is in the order of £170 million per year which exceeds that spent by health and social services.

- Moreover as British surveys have shown, parents of people with a learning disability are more often likely to be engaged in voluntary work to assist others than are other parents. (160)
- Volunteers who give freely of their time to support people with a learning disability make a significant input particularly in the area of leisure and sporting activities e.g. approximately 4,000 men, women and children with a learning disability participate in leisure clubs in Northern Ireland such as Gateway and Special Olympics, which are staffed mainly by volunteers. (56)
- There will be an increased need for volunteer involvement as a consequence of the rise in advocacy and befriending services anticipated in the Equal Lives Review.
- The distinction between volunteers and paid staff can be blurred in fostering and family placement schemes in which a host family looks after a person with a learning disability in their home. Payments are made to cover the extra expense this entails although there is criticism of the low rates of pay on offer. However, most volunteers in these schemes do not want to make money but continue because of the satisfaction and enjoyment they get from it. (101)
- A common outcome is the way the experience enriches the lives of the volunteers. A study of over 200 volunteers who supported athletes at the World Games of Special Olympics in Dublin identified 4 main outcomes; it was an enriching and worthwhile experience; they gained a greater understanding of people with a learning disability; it contributed to a national event in the life of the country and it emphasised people's talents not their disabilities. (161)
- In sum, volunteers are in danger of being overlooked as services become more professionalised. Yet this is one of the proven means of reducing the social exclusion of people with a learning disability and for increasing the quality of their lives. Increased resources and efforts are required to sustain and expand schemes that support volunteers.

Changing Nature of Services

11.8 The changing nature of services detailed at paragraph 11.1 creates challenges and opportunities for workforce development including a trend towards smaller staff teams in services, an increase in lone working, a requirement that staff develop their understanding of the impact of Autistic Spectrum Disorder on people who have a learning disability and the need for training to enable staff to provide highly specialist health interventions.

- The increase in the number of people with a learning disability with additional complex health needs has created a need for additional supports and services if people are to be able to avail of the service provision. Increasing complexity of need in community care with added chronic disease management is currently placing under resourced community health services under great pressure.

> *My daughter is profoundly disabled and needs 24-hour care. The agency that provides respite in my house has been told their staff are not allowed to give her medication. I have to come home while they are there to give her the medicine so I don't really get the break at all.* (2)

- In many special schools this issue has been addressed by having more nurses on site during school time, which has been well received by education staff. **(162)** In day centres some nurses have been employed in other roles but until recently most centres have relied on inputs from nurses on the Community Learning Disability Teams. However, at least one Health and Social Services Trust has appointed a nurse to the day centre staff team; as yet there is no evaluation of the outcomes of this approach.

- Professionals are increasingly undertaking more specialist functions in services which requires them to move into new areas of work, new structures and new working methods for which training and staff support needs are particularly crucial.

- The concept of a Community Learning Disability Team has been a feature of learning disability services in the UK since the 1970s. The form and function of these teams varies widely and there has been very little research undertaken into the effectiveness of the various models despite the fact that they are an expensive component of health and social services provision. The structure of community teams providing services to people with a learning disability is changing across Northern Ireland. Many Trusts have moved away from the formally structured Community Learning Disability Team that provided services to children and adults with a learning disability. A number of different team structures now exist, including Children's Disability Teams, Adult Disability Teams supporting people with all disabilities (but with some team members only supporting people with a learning disability), separate Community Nursing Teams and Community Social Work Teams for people with a learning disability (with varying degrees of collaborative working).

- Whilst considerable literature exists about the requirements for effective team work **(163, 164)**, at present there is no clear evidence on the impact of different team structures in support of people with a learning disability, nor conclusive evidence on the most effective team structure within community learning disability services.

- Responses to consultation confirmed that there is a very variable pattern with some respondents indicating that they did not work in teams but rather as groups of professionals working alongside each other. Consultation feedback also confirmed the need for greater clarity about the composition and function of community teams and the changing role they should play in the future as a consequence of implementation of the Equal Lives Review.

- Ensuring the inclusion of people with a learning disability in community facilities will mean that some staff who support people with a learning disability will have to develop increased knowledge and skills in community profiling, community development and networking.

- As access to Direct Payments increases a larger number of individuals will be directly employing staff to meet their support needs creating new challenges in relation to meeting the training needs of both the employer and employees.

Staff in Mainstream Health Services

11.9 Despite the fact that inclusion has been a policy aim in Northern Ireland since 1995 (7), people with a learning disability continue to encounter persistent difficulties in gaining equity of access to mainstream services as noted earlier. In particular, difficulties have been reported in accessing primary care and acute general hospital services within Northern Ireland. To a large extent these stem from the attitudes of staff in these sectors.

- The views of professionals in primary care towards people with a learning disability and their limited skills in communication, limited preparation or specific training have been identified as factors influencing the service provided to people with a learning disability. Research evidence also shows that people with a learning disability often do not avail of other health services within community settings (eg dentist, optician, audiologist, speech and language therapist, dietician - refer to Chapter 7).

- It is recognised that nurses within acute hospitals also report experiencing difficulties in working with people with a learning disability. Indeed, the National Patient Safety Agency has recently highlighted the seriousness of this situation and after a comprehensive process of consultation within England has identified the care of people with a learning disability in general hospitals as one of their top priority issues. (165)
- Studies consistently report limited confidence and uncertainty about what to do in working with people with a learning disability. Acute care nurses often reported limited knowledge, skills and experience towards caring for people with a learning disability. Likewise a study undertaken in Northern Ireland, which included 167 student therapists (mainly physiotherapists and occupational therapists) reported that they had significantly less confidence and felt more unprepared to work with people with a learning disability than people with a physical disability. (166)
- Evidence is available from within Northern Ireland to show that when primary care and specialist learning disability staff work collaboratively, the health status of people with a learning disability can be improved.

11.10 It will be equally important that staff in mental health services become more skilled in supporting people with a learning disability.

Training and Development

11.11 Whilst many people consulted during the Equal Lives Review highlighted an increase in the range of training and development opportunities available, concern was expressed about the patchy nature of such provision and the relevance of current qualifications to those supporting people with a learning disability.

11.12 Surveys of managers in learning disability services in Northern Ireland have consistently highlighted challenges for them in meeting the training and development needs of Direct Support Workers. Specific training gaps cited include staff training on sexuality and personal relationships, Autistic Spectrum Disorder and addressing challenging behaviours. (135, 136, 167) While the value is acknowledged of National Vocational Qualifications (NVQ) in assessing competence, shortcomings have been identified with current training requirements that focus solely on NVQ attainment without ensuring adequate provision of a coherent learning pathway for staff working with people with a learning disability. The introduction of LDAF has enabled agencies to begin to address this gap and initial evaluations of pilot projects using this framework are promising. (168)

11.13 The only dedicated professional training courses in learning disability are in nursing and psychiatry. Other professionals may take a number of modules or only parts of a module on learning disability as part of their initial training. The University of Ulster has recently introduced a Higher Certificate in Health and Social Care (Learning Disability Studies) although this is primarily intended for staff without formal professional training. There is a need to develop trans-disciplinary postgraduate modules or courses in the field of disability generally or learning disability in particular in order to increase the expertise of professionals working in dedicated learning disability services. The University of Ulster has recently introduced two such courses, one focusing on learning disability and challenging behaviours and the other on learning disability and mental health needs.

Action Required

11.14 The challenges to developing the workforce that will be required to achieve the Equal Lives objectives may be summarised as building a workforce that:

- meets the needs of people with a learning disability and their families
- recognises cultural shifts in services towards supporting people in ways that are person centred, more flexible and based on the Equal Lives values
- addresses problems in staff recruitment and retention
- is sensitive to the particular issues in working with people from ethnic minority communities
- comprises staff who are skilled, confident, competent and well supported by their employers
- develops the capacity of staff in learning disability services to provide leadership within and between a wide range of agencies.

11.15 The perceptions and needs of staff within non-learning disability services must be considered and action taken to provide the support needed for inclusion to become an accepted aim of these services. To be effective collaborative working must go beyond providing information to primary care and acute general hospitals services about what needs to be done; it needs to include practical support, training and sharing of information with staff in these sectors.

11.16 Such collaborative arrangements should be evaluated against the degree to which they result in an increased capacity among mainstream services to support people with a learning disability and must replace families of people with a learning disability or staff in learning disability services providing parallel services to those provided to the wider population.

11.17 The collaborative developments noted above in relation to primary and acute care services will also be necessary for staff in a wide range of other services, such as employment support, further education and housing services; the key point being that the Equal Lives objectives will never be achieved if the knowledge, skills and values are not in place within all mainstream services.

11.18 Health and Social Services Boards and Trusts need to develop greater clarity about the coordination of community learning disability professionals. There is a confused picture at present, which does not form a viable basis for meeting the Equal Lives objectives. In particular for developing the revised working practices that will deliver the new styles of services envisaged in this report. The functions and coordination of community learning disability professionals should therefore be reviewed in light of the proposals in this review by December 2006. **(Recommendation 61)**

11.19 As a matter of urgency the Department of Health, Social Services and Public Safety should develop a regional development strategy for the learning disability workforce. This short-life review should be completed by April 2007. We believe that this strategy should:

- involve all key stakeholders including those in the independent sector
- review the remuneration of staff in relation to other service sector occupations, such as the hospitality industry

- seek to address the needs of small-scale isolated providers
- ensure that the current and future needs of the workforce are addressed particularly the implications for staff in addressing the direction of travel envisaged in this review
- promote increased joint working in addressing training and development needs
- promote the involvement of people with a learning disability and family carers in staff recruitment, training and development
- gather robust data on the workforce including current staff, qualifications held and identification of gaps in the knowledge and skills
- explore the potential application of LDAF for providing a learning pathway that complements NVQs and for up-skilling the learning disability workforce and staff in other settings. **(Recommendation 62)**

11.20 The Department of Health, Social Services and Public Safety currently operates the Training Support Programme (TSP), which provides funding for employers of social care staff in the statutory and voluntary sectors to enable them to meet the training requirements of Government policy. TSP has considerable potential to be used to support the training and development issues for these staff that have been highlighted in the Equal Lives Review. However, criteria for accessing this funding is rigidly linked to attainment of qualifications as determined by the Social Services Inspectorate and the Northern Ireland Social Care Council (NISCC). As has been noted these rigid qualification targets are seen as not being effective in meeting the full range of training challenges that exist in services and that will be exacerbated by the demands of the Equal Lives Review. The role of TSP needs to be revised, the budget available needs to be increased and the criteria for the funding revised in order to support the extensive workforce development challenges we envisage.

11.21 In order to support the involvement of service users in training those in receipt of TSP funding should be required to report on the degree to which they are developing mechanisms for securing the involvement of people with a learning disability in the design and/or delivery of training programmes. **(Recommendation 63)**

11.22 The training needs of family carers and volunteers have not been well met by existing arrangements. It should be incumbent upon those in receipt of TSP funding that mechanisms are set in place to open up access to this provision for these groups where possible. **(Recommendation 64)**

11.23 Finally there needs to be a time limited initiative to promote the leadership and managerial capacity of staff that will be crucial to the implementation of the Equal Lives Review. Priority should be given to proposals for initiatives that will be jointly planned across sectors and settings. **(Recommendation 65)**

11.24 In order to achieve a baseline level of knowledge that may be expected of all Direct Support Workers in adult learning disability services in Northern Ireland, it is recommended that the induction and foundation standards that have been produced by the NISCC become a mandatory requirement of all new entrants to this workforce. In order to ensure that the knowledge base is sensitive to the needs of men and women with a learning disability the attainment of these standards should be assessed through successful completion of LDAF induction and foundation standards as these have been developed with this aim in mind.[9]

11.25 From 1st January 2007 all new Direct Support Workers in learning disability services should be required to meet NISCC standards on induction and foundation within the 6 months of appointment. It is anticipated that this will normally be evidenced by completion of assessment to LDAF standards and be subject to inspection by Health and Personal Social Services Regulation and Improvement Authority (HPSSRIA). **(Recommendation 66)**

11.26 In order to produce health gains for people with a learning disability, to promote improved access to mainstream health and social services and to address the deficiencies that have been highlighted in professional training, we recommend that professional training is required to ensure that generically trained health and social services professionals (medicine, Allied Health Professionals, nursing, social work) should receive a minimum of awareness raising training on learning disability issues during their pre-qualification education. **(Recommendation 67)**

11.27 In order to enhance the status of working with people with a learning disability as a positive career choice and to encourage recruitment in the paid workforce, volunteering and community service, a publicity strategy should be developed and implemented that promotes the positive features of working with people with a learning disability. **(Recommendation 68)**

11.28 As has been noted throughout the Equal Lives Review successful community integration will require that members of the public and staff in agencies beyond health and social services develop a greater understanding of the strengths, needs and contribution that people with a learning disability can make to community life. In order to stimulate the development of such an understanding it is proposed that Department for Social Development, Department of Education and Department for Employment and Learning identify tangible action that they can take to promote joint training and awareness raising amongst the agencies that are accountable to them. **(Recommendation 69)**

11.29 Objectives 10 and 11	**Recommendations**
Recommendation 61	HSS Boards and Trusts should agree the role, composition, configuration and functions of Community Learning Disability Teams in light of the proposals in the Equal Lives Review by December 2006.
Recommendation 62	By April 2007 a regional workforce development strategy should be produced in partnership with employers from the independent and statutory sectors that identifies the workforce implications of the Equal Lives Review and sets out a clear strategy for addressing them.
Recommendation 63	All service providers who receive funding from the Department of Health, Social Services and Public Safety Training Support Programme should be required to evidence how people with a learning disability have been involved in the design, delivery and/or evaluation of training programmes provided on learning disability specific issues.

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[9] Work is ongoing on extending the LDAF to children's services. It will be necessary when this work is completed to consider its relevance and application to children's services in Northern Ireland

Recommendation 64 Service providers who receive Training Support Programme funding should be required to demonstrate that arrangements are in place to open access to the training provision to family carers, volunteers and people with a learning disability where possible.

Recommendation 65 Funding should be allocated to the Review Implementation Steering Committee for a Leadership Innovation Fund to which all agencies and professions might apply, designed to promote interagency initiatives that develop the leadership and managerial capacity in organisations to deliver on the new vision in the Equal Lives Review.

Recommendation 66 From 1 January 2007 all new Direct Support Workers in learning disability services should be required to meet the Northern Ireland Social Care Council standards on induction and foundation within the first year of appointment. It is anticipated that this will normally be evidenced by completion of assessment to LDAF standards and be subject to inspection by the Health and Personal Social Services Regulation and Improvement Authority.

Recommendation 67 All generically trained health and social services professionals (medicine, Allied Health Professionals, nursing, social work) should receive at a minimum awareness raising training on learning disability.

Recommendation 68 A publicity strategy should be developed and implemented that promotes the positive factors of working with people with a learning disability and encourages greater participation in volunteering and community service.

Recommendation 69 Department of Education, Department for Social Development and Department for Employment and Learning should develop measures to encourage awareness raising and improved training on learning disability amongst agencies that they fund to support equity of access by people with a learning disability to their provision. These measures should include the development of joint training opportunities with health and social services agencies.

MANAGING CHANGE: IMPLEMENTATION

Chapter 12

Improved inter-agency working would result in better service provision to those with a learning disability and an enhancement of their opportunity and quality of life.
Manager of a Citizens Advice Bureau.

12.1 The Equal Lives Review sets out an ambitious change programme that will require commitment and leadership at all levels in organisations throughout Northern Ireland. We anticipate that the implementation of the recommendations of the Equal Lives Review will involve a fundamental shift towards more person centred ways of working and a determined effort to remove barriers to inclusion in existing structures, systems and working practices. The Equal Lives Review has concluded that many of the aspirations in the 1995 Review were appropriate and that it can usefully be built upon to deliver on the Equal Lives objectives. However, our consultation indicates that major weaknesses in the 1995 Review included:

- the absence of transparent resource commitments to implement the Review's recommendations
- the lack of a robust implementation process
- the continuation of organisational impediments to progress.

12.2 Many of the needs of people with a learning disability and their family carers are best met at an individual, face-to-face level. However, the way in which these services are delivered is heavily influenced by the organisational structures in which they are provided. Different organisations can be involved in attempting to meet the diversity of needs and aspirations. Agencies have different funding sources as well as different management and staffing structures and contrasting ways of working. Therefore, it can be difficult for them to co-ordinate their services even when they are working in the same geographical area. These difficulties are further compounded when service priorities are set and service planning is undertaken without consultation with potential partner agencies.

12.3 In this chapter we will highlight issues and concerns relating to organisational arrangements in support of people with a learning disability and outline our proposals for supporting the implementation of the Equal Lives Review.

Objective 12 To promote improved joint working across sectors and settings in order to ensure that the quality of lives of people with a learning disability is improved and that the Equal Lives values and objectives are achieved.

Issues and Concerns

Organisational Structures

12.4 There is a wide range and growing number of organisations that work to support citizens in Northern Ireland. Many of these organisations are for everyone and therefore, they should be open to supporting people with a learning disability. Others are specific to people with a learning disability and in recent years their number has also grown significantly.

12.5 Some organisations have a regional remit in that they cover all of Northern Ireland. Others are responsible for designated geographical areas such as Health and Social Services Boards, while others cover particular districts, such as Health and Social Services Trusts or District Councils. Finally there are others, which work at a more local level, such as a special school or a day centre.

Present Service Structures For People With A Learning Disability

12.6 All Government departments have responsibilities to people with a learning disability just as they have to all other citizens. This responsibility was reinforced by Section 75, Northern Ireland Act (1998), which placed a duty on public authorities to have *due regard to the need to promote equality of opportunity between persons with a disability and persons without.* The Department of Education and Department of Health, Social Services and Public Safety have traditionally taken a leading role in addressing the needs of people with a learning disability for whom they have specific legal responsibilities. On occasions this has had an adverse effect in terms of limited impetus in other Departments to ensure that their activities effectively targeted people with a learning disability.

12.7 While a number of voluntary organisations also operate at a regional level there are no regional organisations led and managed by people with a learning disability.

12.8 The Department of Health, Social Services and Public Safety and Department of Education oversee the work of 4 Health and Social Services Boards and 5 Education and Library Boards at an area level. Unfortunately the geographical areas covered by these sets of Boards are not the same. Within Health and Social Services Boards, there are a number of programmes of care, of which learning disability is a distinct programme. However, other programmes of care also have some responsibility for people with a learning disability as they do for all other citizens although this is often not well defined. Likewise, each Education and Library Board has a senior manager with responsibility for Special Educational Needs.

12.9 The Boards act largely as planning and commissioning bodies; contracting with local agencies - that is Health and Social Services Trusts and Schools - to directly provide services.

12.10 Health and Social Services Trusts in turn may contract with voluntary and private sector providers for the delivery of certain services that usually cover a particular locality. Some of these agencies also work in different Trust and Board areas.

12.11 A number of organisations exist to further collaboration and co-ordination among the voluntary sector throughout Northern Ireland. These include the Association of Real Change (ARC), Children in Northern Ireland and Northern Ireland Council for Voluntary Action (NICVA).

Participation by People with a Learning Disability or Carers in Service Planning and Provision

12.12 There are few formal organisations to represent the views of people with a learning disability or family carers. Consequently there is little tradition of service providers working jointly with people with a learning disability or family carers in the provision of services.

- There is general agreement that greater participation in the planning of learning disability services would result in better services.
- There is a greater emphasis on consultation rather than participation, where consultative processes are separated out from Trust business planning arrangements.
- The value of integrating consultative processes with policy development mechanisms has been evidenced by the role played by Equal Lives group members in the Equal Lives Review, which clearly demonstrated their capacity to be active participants in the process with strongly held views on topics that may receive less attention from professionals. (1)

Reform of Public Administration in Northern Ireland

12.13 A major Review of Public Administration (RPA) commenced in June 2002. The RPA has highlighted a common concern about

> *a continuing growth in the number of organisations involved in public administration, which not only absorbs resources, but makes it more difficult for the public to identify and contact the appropriate source of advice and support and a lack of co-ordination between sectors and organisations at all levels where there is a need to work together on specific issues or personal cases.* (169)

12.14 The RPA team has published its final stage consultation document. A two-tier model is proposed, with a regional tier encompassing the Assembly, Government departments and regional authorities. The second, sub-regional tier covers organisations that would ideally have the same boundaries, including councils, health bodies, other sub-regional bodies and sub-regional delivery units of regional bodies. There is also support for an enhanced role for both the private sector and the voluntary and community sectors. Given the significant changes to the structure of the public sector in Northern Ireland, that are proposed by the RPA, we consider it premature to recommend far reaching changes at this stage. Rather we will set out considerations that we hope will help inform the future reform process.

Developing Policy for Learning Disability Services in Northern Ireland

12.15 Despite the growing emphasis on joint working in Government policy statements, the main method of service planning and delivery in support of people with a learning disability remains that of independent working by different agencies.

12.16 In the 1995 Review of Policy for People with a Learning Disability, it was noted that other Government departments and agencies have a lead role to play, such as housing, further education, training for and support in employment, and leisure. It recommended

Good liaison arrangements between all of the agencies involved are necessary both at the strategic planning level and at the point of service delivery to ensure the development and implementation of compatible and co-ordinated strategies. (7)

12.17 As has been noted throughout this report the Equal Lives Review has identified serious shortcomings in achieving this aim.

12.18 In recent years the Department of Health, Social Services and Public Safety has identified the need for inter-departmental working to meet a range of Government policy objectives in the broad field of health and various interdepartmental working groups have been set up in furtherance of these aims; most notably the Ministerial Group on Public Health. (170) However, formal interdepartmental working appears not to have occurred to any great extent in learning disability, although there have been positive developments in relation to interdepartmental groups on Early Years and Transitions, which have addressed the needs of young people and children with a disability.

12.19 Since the last Review of Learning Disability Services all 4 Health and Social Services Boards have produced policy statements on service provision. All Boards endorsed the need for inter-sectoral working with voluntary and statutory providers and also for consultations and planning to be done with service users and family carers.

12.20 A study carried out by the University of Ulster for the Equal Lives Review confirmed that joint working is happening to some extent on the ground. The benefits were seen to outweigh any potential drawbacks and they centred mainly on the gains for people with a learning disability in getting better co-ordinated services. This implies recognition that services working independently of one another are providing a poorer quality of service than they could be delivering.

12.21 The research study confirmed the messages from other submissions made to the Equal Lives Review that there will need to be a determined and committed effort to ensure that joint working is an essential feature of future service provision in Northern Ireland. In addition, our review of work undertaken to implement changes to policy affecting people with a learning disability elsewhere in the UK and the Republic of Ireland confirms that robust implementation arrangements are essential if the changes are to succeed.

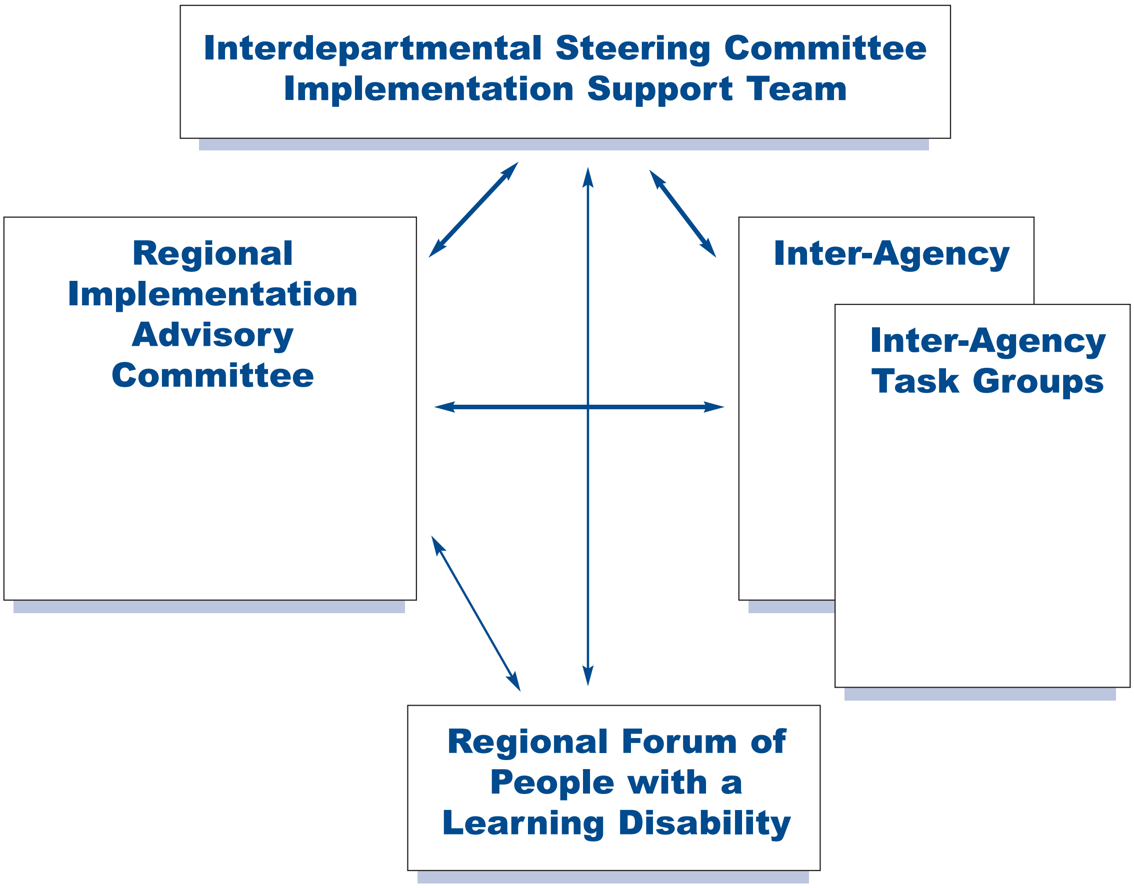
12.22 The proposals that follow acknowledge that, in the context of the RPA, there is a need for us to highlight principles that should underpin any future restructuring to ensure that the needs of people with a learning disability and indeed other minority groups are addressed. These proposals are, therefore, offered to inform the ongoing work of the RPA unless accompanied by a specific recommendation that we believe should be enacted regardless of the nature of restructuring that will follow the outcomes of the RPA.

Action Required

Review Implementation Arrangements

12.23 The Equal Lives Review has highlighted a need for a major development of services and some reconfiguration of existing provision. In Figure 12 we outline the structures that we believe are required to ensure that this happens effectively and in accordance with the core values of the Equal Lives Review. This model aims to facilitate the processes of consultation, co-ordination and implementation, which arguably are missing in existing structures.

Figure 12: Proposed Implementation Arrangements



12.24 Particular efforts need to be made to promote the meaningful involvement of people with a learning disability in future arrangements. At present the number of organisations doing this is small, as is the development of advocacy in its various forms. There is no regional forum for people with a learning disability in Northern Ireland and very limited public money is spent on the promotion of advocacy and in supporting people with a learning disability to participate meaningfully in planning groups and committees. Moreover there is a need to promote advocacy at a more local level as well, so that people with a learning disability have increased opportunities to access mainstream as well as specialist services.

12.25 The involvement of carers is arguably further advanced in service planning, but this is variable across Northern Ireland. When it has occurred, the outcomes are broadly positive, which should encourage provider and commissioning agencies to expand their engagement with carers. This can be achieved by ensuring they are represented alongside professionals in committees and working groups. It is vital though that these representatives are assisted in ensuring the broader population of carers are informed of these processes and that mechanisms are in place to reflect their views.

12.26 There are a number of clear messages to emerge from the Equal Lives Review about how joint working can be promoted. These are already operational in Northern Ireland, albeit in contexts other than learning disability, but they do have the support of the agencies consulted as part of the Equal Lives Review. We anticipate that there is a need for 2 levels of joint working: inter-departmental and local inter-agency. This simple structure should suffice given the size of Northern Ireland and the small number of people with a learning disability.

12.27 Moreover it is important that these structures incorporate the 3 processes of consultation, co-ordination and implementation.

12.28 There is widespread agreement on the benefits of having an Interdepartmental[10] group to take forward the recommendations emerging from the Equal Lives Review. Membership of this Interdepartmental Steering Committee would comprise representatives from each relevant Government Department. The Minister should chair the meetings of the Interdepartmental Steering Committee on 4 occasions per annum. **(Recommendation 70)**

12.29 The Interdepartmental Steering Committee would also have responsibility for advising Departments on the commissioning of both existing and new learning disability services. In doing so they would be informed by representatives of users, carers, local Inter-Agency Task Groups and service providers who would comprise a Regional Implementation Advisory Committee. The Regional Implementation Advisory Committee would provide an opportunity to identify common issues across Northern Ireland, as well as sharing in good practice initiatives. It would monitor the work of the local Inter-Agency Task Groups as well as provide a forum for debate on controversial issues and on the development of new service initiatives envisaged by the Equal Lives Review. The work of the Regional Implementation Advisory Committee should be supported by a Development Fund to stimulate change and innovation in the implementation of the Equal Lives Review.

12.30 Both committees would need to be serviced by a small team of full-time staff - an Implementation Support Team - preferably to include staff seconded from agencies outside of the Civil Service, who have particular experience and expertise in assessing and meeting the needs of people with a learning disability and who can provide credible advice and guidance to local groups in the production and implementation of local plans and change initiatives. **(Recommendation 71)**

12.31 There may also be some value in designating one person with lead responsibility for the operations of this team, who is accountable (has direct access) to the Minister chairing the Interdepartmental Steering Committee.

12.32 The Regional Implementation Steering Committee and Implementation Support Team would liaise closely with a Regional Forum for People with a Learning Disability. They would produce accessible annual reports and meet the Forum at least annually to plan the programme of work for the coming year. **(Recommendation 72)**

12.33 The Implementation Support Team could be time-limited appointments for a 5-year period in order to establish the new structures and to help them to bed down. The ultimate goal would be for these new arrangements to become embedded into mainstream structures, although the need for an interdepartmental group would probably continue as would the Regional Forum for people with a learning disability.

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[10] At a minimum this should consist of DHSSPS, DENI, DEL, DSD, OFMDFM and Department of Culture, Arts and Leisure (DCAL).

12.34 These joint working arrangements should be replicated at a local level. Inter-Agency Task Groups should be set up at an agreed local level. Initially we propose that 4 Task Groups be established possibly based on existing Health and Social Services Board areas, which may sub-divide for particular purposes such as supporting the production of Day Care Development Plans. **(Recommendation 73)**

12.35 The Inter-Agency Task Groups' remit would be to review existing provision in their area and to plan the range of services available to people with a learning disability and their families within the context of the Equal Lives values and objectives. These groups could cover the full age range of people with a learning disability, although they will need to liaise with the 4 area inter-agency groups that are already operational for children's services if they continue in operation.

12.36 The Inter-Agency Task Groups should have representatives of existing statutory, voluntary and private agencies and would include Health and Personal Social Services, Education and Library Boards, Further Education Colleges, Department for Employment and Learning, Northern Ireland Housing Executive, Community Education and Leisure Services of District Councils, along with user and carer representatives and their advocates. Initially they would be convened and supported by Health and Social Services Boards, but within 1 year, the groups will have identified the means for achieving co-ownership.

12.37 The groups would be required by the Interdepartmental Steering Committee to prepare Joint Learning Disability Service Plans along the lines of those required in Great Britain and the Republic of Ireland. These will form the basis of funding bids and the commissioning of local services. They would also inform the form, role and location of specialist learning disability provision and access to other special needs services.

12.38 The proposed Implementation Support Team and the Regional Implementation Advisory Committee would have a major role to play in establishing and supporting these groups.

North-South and East-West Relationships

12.39 This proposed structure would also facilitate greater linkages with learning disability interests elsewhere in these islands; notably between the Governmental Interdepartmental Groups and between the different national fora for people with a learning disability.

12.40 Indeed it could be argued that the lack of these structures within Northern Ireland has contributed to the relative isolation of learning disability services here from elsewhere in these islands.

Specific Focus on Learning Disability

12.41 There has been a long history in Northern Ireland of ring-fencing public funding to services specifically for people with a learning disability. Ring-fenced funding can be justified on various grounds. The needs of this population are complex and life-long even though the numbers are relatively small. Moreover they are distinctive when taken as a whole especially from other disabling conditions and mental health needs. Services are still under-developed and development monies are more easily targeted if they have a specific focus. Major changes in policy are more easily implemented within a distinct domain.

12.42 We recommend that ring-fenced funding continues within the Department of Health, Social Services and Public Safety and Department of Education, even though the way in which these monies are spent could change radically in the coming years as they have done in the past. This also necessitates having transparent accountability systems in place to demonstrate that the monies are spent on the purposes for which they were given and the outcomes achieved.

12.43 There is also logic in extending this concept to other funding departments, especially in the light of Section 75 duties placed upon public bodies. At a minimum this would demonstrate that these citizens are getting at least their fair share, but also make more transparent the contribution they are making to positively responding to the particular needs of these citizens. **(Recommendation 74)**

12.44 This is not to imply that these funding streams should be managed separately. Indeed the evidence suggests that local services can be more efficiently delivered if they are jointly commissioned using pooled funding, as is the case in Great Britain. This is starting to happen with the new Supporting People arrangements in Northern Ireland and this model could be extended to other aspects of people's lives such as transition planning, training and employment services, and leisure initiatives.

12.45 In view of the negative impact that the absence of robust implementation structures had on the success of the 1995 Review, it is the view of the Learning Disability Working Committee that work on implementing each of the following recommendations has to be commenced immediately if the objectives of the Equal Lives Review are to be achieved.

12.46 Objective 12 Recommendations

Recommendation 70	An Interdepartmental Steering Committee should be established by January 2006 to promote joint working and oversee the implementation of the Equal Lives Review recommendations.
Recommendation 71	An Implementation Support Team should be established by November 2005 to support work being undertaken to implement the Equal Lives Review.
Recommendation 72	A Regional Forum for People with a Learning Disability should be established by January 2006.
Recommendation 73	Inter-Agency Task Groups should be established by June 2006 to drive change at a local level and produce local plans in accordance with the Equal Lives values and objectives.
Recommendation 74	Ring-fenced funding continues within Department of Health, Social Services and Public Safety and Department of Education and the potential is explored for extending this to other departments to underpin the implementation of the Equal Lives Review.

Prioritisation of Other Recommendations

12.47 This report has highlighted that people with a learning disability in Northern Ireland do not enjoy equality of opportunity and that they are often excluded from the opportunities that other citizens enjoy. As has been shown some progress has been made but in order to resolve fully the difficulties outlined there will be a need for a major and co-ordinated development programme over the next 15 years.

12.48 The Equal Lives report has made 74 recommendations to take forward its vision for the future. Full implementation of these recommendations will cost approximately £175 million additional over the change period. (171) It is recognised that these large sums of money are not immediately available and accordingly this section of the Equal Lives report will set out some immediate and medium -term objectives. While change will be costly and will take time there must be an immediate and ongoing commitment to making financial resources available if the change process is to be real. While the report recognises the need to reconfigure and better target existing resources, the level of change and modernization envisaged will not happen without this commitment.

12.49 To maximise the impact of change it will be essential to progress each of the report objectives in tandem. While some recommendations will not require funding they will require considerable investment of planning time from staff and will also have to be incrementally introduced.

12.50 It is now intended to order each of the Equal Lives Review recommendations placing a priority rating against them. Priority ratings agreed were as follows:

i. Pre-Implementation Support

ii. Immediate Planning - to be started forthwith

iii. Immediate Resourcing - 2006 - 2012

iv. Medium-term Resourcing - 2012 - 2020.

Principles Guiding Prioritisation Process

12.51 Recommendations will be prioritised if they:

i. provide support for family carers

ii. maximise HPSS and other public funding streams e.g. Supporting People

iii. show that they can prevent inappropriate hospital admissions

iv. release money from current services which are considered to be no longer fit for purpose

v. promote effective access to all services across Northern Ireland

vi. maintain and build upon existing interagency collaborations.

12.52 It is clearly acknowledged that the recommendations are not mutually exclusive and therefore planning for delivery of all the recommendations must commence immediately. The Learning Disability Working Committee accept that implementation of all the recommendations by necessity will be incremental in nature.

Pre-Implementation Support

- Appointment of Implementation Support Team by November 2005
- Establishment of Interdepartmental Steering Committee by January 2006
- Establishment of Regional Forum for People with a Learning Disability by January 2006
- Establishment of Inter-Agency Task Groups by June 2006

- Agreement that ring-fenced funding continues within Department of Health, Social Services and Public Safety and Department of Education and the potential explored for extending this to other departments. **(Recommendations 71,70,72,73,74)**

Immediate Planning

12.53 Those recommendations that fit into Immediate Planning are as follows:

- Development of joint planning and bidding mechanisms by the Departments of Education and Health, Social Services and Public Safety for services for children and young people with a learning disability by January 2007
- Development of a regional strategy for early intervention by the Departments of Education and Health, Social Services and Public Safety by June 2007
- Promotion of Supported Employment Services by Department for Employment and Learning
- Clear assessments of future housing needs for people with a learning disability completed and agreement reached on a 3 year funding strategy to resource housing and support arrangements by Department for Social Development and Department of Health, Social Services and Public Safety
- Detailed knowledge accumulated and disseminated on the range of assistive technology that is available to enrich the capacity of people with a learning disability to lead more independent lives in the community by housing planners
- Development of a strategy to increase opportunities for people with a learning disability to own their own homes by the Department for Social Development
- Revised procedures and criteria for applying for Disabled Facilities Grants
- Mechanisms established to ensure the increased use of floating support by the Department for Social Development and the NI Housing Executive
- Review completed of the Motability Scheme
- Regional Framework for Health Improvement of people with a learning disability produced by the Department of Health, Social Services and Public Safety
- Equipment and wheelchair provision budgets increased to meet significant additional demand
- Health Improvement Plans reviewed by HSS Boards
- Specific reference to the needs of and impact upon people with a learning disability within all generic health strategies, published at Department, HSS Board and Trust level
- Awareness raising and improved training on learning disability in place amongst agencies funded by the Department of Education, Department for Social Development, and Department for Employment and Learning
- Commissioned programme of research and service evaluation established in collaboration with the R & D Office

- Identification of the need for permanent placements for children and young people with a learning disability and production of strategies by Health and Social Services Boards to address them by March 2006
- Costed Development Plans for day centres produced by each Health and Social Services Trust by March 2007

(Recommendations 9, 8, 18, 23, 32, 33, 34, 35, 36, 37, 38, 44, 68, 60, 4, 17)

Immediate Resourcing

12.54 The following recommendations have been agreed as falling within this area:

- Opportunity to have a PCP which incorporates Heath Action Planning is in place for all persons with a learning disability who are in contact with HPSS agencies by January 2009
- Arrangements in place from January 2006 to prioritise person centred planning concerned with:
    - development and delivery of Family Support Plans
    - development and delivery of Early Intervention Plans
    - Transitions Plans
    - Futures Plans
- Establishment of independent advocacy services
- Establishment of Family Support Fund and extension of range and volume of support available to families
- Development of community based assessment and treatment services for children and young people with severe challenging behaviours and/or mental health problems
- Mechanisms in place to ensure that information on services, benefits and other sources of help is automatically supplied to families at diagnosis/birth of their child
- Commissioning requirement in place detailing that providers of any services evidence how information will be provided in an accessible format appropriate to the needs of the individuals being supported
- Establishment of Transition Services for all young people who have a statement
- Personal relationships education available in all services for people with a learning disability with training offered to staff and support to parents
- Development of community based assessment and treatment services for men and women with a learning disability who have specific mental health needs and/or challenging behaviours
- Production of regional guidelines on the management of challenging behaviours within services by December 2007 by the Department of Health, Social Services and Public Safety in partnership with service providers
- All people with a learning disability living in a hospital relocated to the community by June 2011

- Funds provided to ensure that on average 80 people are resettled per annum over the 5-year period from 2006 to 2011
- Resourced and implemented arrangements in place to provide emergency support and accommodation for persons with a learning disability by January 2008
- Mechanisms in place to ensure that all new housing with support provision for people with a learning disability is for no more than 5 individuals with a learning disability within the same household
- Additional 100 supported living places per annum developed for the next 15 years to enable people to move from family care without having to be placed in inappropriate settings
- Clear and formalised arrangements set in place by each General Practice facility and Acute General hospital to facilitate equity of access to services for people with a learning disability
- Link person identified within Community Learning Disability Teams to work with each General Practice
- Establishment by General Practices of robust medical records and health data about people with a learning disability on their practice registers
- Strategic plan produced by the Department of Health, Social Services and Public Safety and HSS Boards to address current deficiencies in services and future service provision for older people with a learning disability and their families
- Development of arrangements to enable people with a learning disability who have dementia to access support and expertise from mainstream dementia services
- £300,000 per annum ear-marked by the Department of Health, Social Services and Public Safety between 2006 and 2009 to increase uptake of Direct Payments
- Policy initiative from OFMDFM in place to reduce the likelihood of bullying experienced by people with a learning disability
- Agreement reached by HSS Boards and Trusts on the role, composition, configuration and functions of Community Learning Disability Teams by December 2006
- Production of a regional workforce development strategy by April 2007
- Establishment of a Leadership Innovation Fund by the Interdepartmental Steering Group
- Arrangements set in place for all new Direct Support Workers in learning disability services to meet the Northern Ireland Social Care Council standards on induction and foundation evidenced by completion of assessment to LDAF standards by January 2007
- Mechanisms set in place for young people with a learning disability to be equipped with skills to use public transport where possible through appropriately targeted independent travel training programmes by Department of Education and Department of Health, Social Services and Public Safety
- Arrangements set in place to ensure that the regional transport strategy ensures that people with a learning disability can access local transport by the Department for Regional Development
- Arrangements set in place to ensure that access to local leisure and recreational services is promoted and co-ordinated led by District Councils

- Clear statements produced on targeting provision for play, sports, arts and leisure opportunities for children and young people with a learning disability by the Department of Culture, Arts and Leisure, Arts Council, Sports Council, Education and Library Boards, Youth Council and District Councils

- Review completed of the effectiveness of programmes of learning for children and young people with special educational needs in relation to issues of personal safety and personal relationships by the Department of Education and Education and Library Boards

- Arrangements made for mainstreaming lessons learned from the pilot projects on inclusion by the Youth Service

- Arrangements made for monitoring the effectiveness of all authorities in meeting their inclusion objectives for children and young people with a learning disability by the Commissioner for Children and Young People

- Revised funding arrangements set in place by Department for Employment and Learning so that FE Colleges are able to increase significantly the number of full-time places available to students who have a Statement of Severe Learning Disability, to undertake a 3 year accredited course

- Review completed of the use of employment, skills and disability programmes by people with a learning disability by Department for Employment and Learning

- Review completed by public sector employers of recruitment practices to open up employment opportunities for men and women with a learning disability

(Recommendations 54, 40, 56, 1, 2, 5, 57, 6, 7, 14, 25, 27, 47, 28, 29, 31, 41, 42, 43, 50, 52, 53, 55, 26, 61, 64, 65, 21, 22, 24, 10, 12, 13, 11, 15, 20, 19)

Medium term resourcing

12.55 The recommendations that fall into this area are:

- Establishment of multi-agency centres, which provide a clear pathway to help for parents of children with a learning disability by Health and Social Services Trusts in partnership with Education and Library Boards and the community and voluntary sector

- Revised funding arrangements set in place by the Department for Employment and Learning to enable more part-time places to be created in FE for older students

- Arrangements secured for all accommodation for people with a learning disability under 60 years of age to be for no more than 5 people by January 2013

- Resources made available from within primary care to appoint a Health Facilitator for each 110-120,000 population by December 2009

- Arrangements secured for the majority of referrals, because of mental health problems, of people with high levels of adaptive functioning/mild learning disability to access, with support from dedicated learning disability services if required, mainstream mental health services by December 2010

- Arrangements set in place by the Health and Personal Social Services Regulation and Improvement Authority to measure delivery of positive personal outcomes by services

- Arrangements set in place for all generically trained health and social services professionals to receive awareness raising training relating to people with learning disability during their pre-qualification education

(Recommendations 3, 16, 30, 39, 46, 59, 66)

Conclusion

12.56 We have set out an ambitious programme for change in the Equal Lives Review, which we believe sets out a clear policy direction for people with a learning disability. The Equal Lives values and objectives should form the benchmarks by which future policy and service developments are measured.

12.57 The objectives and recommendations that we have made cannot be met within current resources and organisational systems. There is a need to change both the use of existing resources and to secure additional funding if the Equal Lives objectives are to be achieved. In addition all those who work with people with a learning disability in both specialist and mainstream settings will need to review how they work, and where necessary, to develop new styles of working that are based on ensuring that the voices of people with a learning disability and their family carers have a greater influence and improved approaches to working in partnership.

12.58 The enthusiasm and dedication that has been evident from the many hundreds of people who have participated in the Equal Lives Review demonstrates that there is a strong commitment to improve the quality of lives of people with a learning disability and their families. The challenge now will be to ensure that the aspirations contained in this Review are translated into action across Northern Ireland in a way that ensures that people with a learning disability really can experience equal lives in the future.

OBJECTIVES AND RECOMMENDATIONS

Annex A

OBJECTIVE 1	**To ensure that families are supported to enjoy seeing their children develop in an environment that recognises and values their uniqueness as well as their contributions to society.**
Recommendation 1	Each Trust should have established arrangements for the development of Family Support Plans, which must be delivered through a co-ordinated strategy that monitors outcomes and identifies unmet needs.
Recommendation 2	Over the next 5 years providers should be resourced to extend the volume and range of emotional and practical help to support families. Their proposals should be considered within the context of Children's Services Planning and be aimed at assisting the maximum number of families. An ear-marked fund of up to £2 million recurrent each year for 5 years should be made available to fund proposals that best meet the Equal Lives values and objectives. The outcomes from this Family Support Fund should be carefully evaluated and used to inform future commissioning decisions in support of family carers.
Recommendation 3	Health and Social Services Trusts in partnership with Education and Library Boards and the community and voluntary sector should establish multi-agency centres, which provide a clear pathway to help for parents of children with a learning disability.
Recommendation 4	By March 2006 each Health and Social Services Board should identify the need for permanent placements for children and young people with a learning disability and produce strategies to address them. While the focus should be on innovative means of developing and supporting specialist fostering, it may be necessary to commission intensive care provision for small numbers of children who can not be placed in family settings.
Recommendation 5	Community based assessment and treatment services should be developed for children and young people with severe challenging behaviours and/or mental health problems. The service should encompass a small short-stay residential provision and community behavioural support services that provide outreach to families, schools and community based agencies.

OBJECTIVE 2 **To ensure that children and young people with a learning disability get the best possible start in life and access opportunities that are available to others of their age.**

Recommendation 6 Each HSS Trust should set in place mechanisms to ensure that information on services and how to access them, benefits and support groups and other sources of help is automatically supplied to families at diagnosis/birth of their child.

Recommendation 7 Each HSS Trust should establish arrangements for the development of an Early Intervention Plan, which includes details of a key worker, for each child with a learning disability at his/her birth/diagnosis.

Recommendation 8 By June 2007 the Departments of Education and Health, Social Services and Public Safety should develop a regional strategy for early intervention.

Recommendation 9 By January 2007 joint planning and bidding mechanisms should be developed by the Departments of Education and Health, Social Services and Public Safety for services for children and young people with a learning disability.

Recommendation 10 The Department of Culture, Arts and Leisure, Arts Council, Sports Council, Education and Library Boards, Youth Council and District Councils should produce clear statements outlining how they are targeting provision for play, sports, arts and leisure opportunities for children and young people with a learning disability.

Recommendation 11 The Youth Service should mainstream the lessons learned from the pilot projects on inclusion and provide the support to ensure that young people with a learning disability get involved in decision-making processes in youth and other civic activities.

Recommendation 12 The Department of Education and Education and Library Boards should review the effectiveness of the programmes of learning for children and young people with special educational needs in relation to issues of personal safety and personal relationships. This should be supported with awareness programmes for parents and for others involved with children and young people.

Recommendation 13 The Commissioner for Children and Young People should be requested to monitor the effectiveness of all authorities in meeting their inclusion objectives. To facilitate this, the relevant departments should produce an Annual Report on the implementation of action plans.

OBJECTIVE 3 **To ensure that the move into adulthood for young people with a learning disability supports their access to equal opportunities for continuing education, employment and training and that they and their families receive continuity of support during the transition period.**

OBJECTIVE 4 **To enable people with a learning disability to lead full and meaningful lives in their neighbourhoods, have access to a wide range of social, work and leisure opportunities and form and maintain friendships and relationships.**

Recommendation 14 That Transition services are established for all young people who have a statement to support parents and young people to develop a transitions plan and ensure recommendations are carried through. Careers advice restructuring should support this proposal and provide an ongoing support to 22 years.

Recommendation 15 The Department for Employment and Learning will ensure that revised funding arrangements are in place so that FE Colleges are able to increase significantly the number of full-time places available to students who have a Statement of Severe Learning Disability, to undertake a 3 year accredited course.

Recommendation 16 In order to afford lifelong learning opportunities the Department for Employment and Learning should ensure that revised funding arrangements will enable more part-time places to be created in FE for older students. Access to FE by people with a learning disability should be monitored and we welcome the intention of the Department for Employment and Learning to do so.

Recommendation 17 By March 2007 each Health and Social Services Trust should have produced a costed Development Plan for each day centre they provide or commission.

Recommendation 18 The Department for Employment and Learning, in consultation with other relevant Departments, should promote the introduction of dedicated Supported Employment services across Northern Ireland.

Recommendation 19 Public sector employers should review their recruitment practices, as required by equality legislation to open up employment opportunities for men and women with a learning disability.

Recommendation 20 Department for Employment and Learning should review the use of its employment, skills and disability programmes by people with a learning disability to remove structural barriers to participation and identify how they could promote better outcomes.

Recommendation 21 Department of Education and Department of Health, Social Services and Public Safety should ensure that young people with a learning disability are equipped with skills to use public transport where possible through appropriately targeted independent travel training programmes. Where possible these should become part of the curriculum and continuing education plans for young adults.

Recommendation 22 Department for Regional Development should ensure that the regional transport strategy ensures that people with a learning disability can access local transport.

Recommendation 23 The Motability Scheme requires reviewing to ensure an appropriate, affordable solution for those who need to travel in their wheelchair along with other family members.

Recommendation 24 Access to local leisure and recreational services should be promoted and co-ordinated led by District Councils.

Recommendation 25 Personal relationships education should be available in all services for people with a learning disability with training offered to staff and support to parents.

Recommendation 26 OFMDFM should co-ordinate a policy initiative to reduce the likelihood of bullying experienced by people with a learning disability, both in specialist settings and the wider community, notably schools. The development of anti-bullying strategies would be a positive first step.

OBJECTIVE 5 **To ensure that all men and women with a learning disability have their home, in the community, the choice of whom they live with and that, where they live with their family, their carers receive the support they need.**

Recommendation 27 By June 2011, all people with a learning disability living in a hospital should be relocated to the community. Funds need to be provided to ensure that on average 80 people will be resettled per annum over the 5-year period from 2006 to 2011.

Recommendation 28 With immediate effect, all commissioners should ensure that they have resourced and implemented arrangements to provide emergency support and accommodation for persons with a learning disability. Hospitals will not provide this service from 1st January 2008.

OBJECTIVE 6 **To ensure that an extended range of housing options is developed for men and women with a learning disability.**

Recommendation 29 With immediate effect, all new housing with support provision for people with a learning disability should be for no more than 5 individuals with a learning disability – preferably less - within the same household.

Recommendation 30 By 1 January 2013 all accommodation for people with a learning disability under 60 years of age should be for no more than 5 people.

Recommendation 31 An additional 100 supported living places per annum for the next 15 years should be developed to enable people to move from family care without having to be placed in inappropriate settings.

Recommendation 32 Department for Social Development and Department of Health, Social Services and Public Safety should develop clear assessments of future housing needs for people with a learning disability including those who currently live with their families and agree a continuous 3 year funding strategy to resource housing and support arrangements.

Recommendation 33 Housing planners should accumulate and disseminate detailed knowledge on the range of assistive technology that is available to enrich the capacity of people with a learning disability to lead more independent lives in the community.

Recommendation 34 A strategy should be developed by the Department for Social Development to increase opportunities for people with a learning disability to own their own homes where this is a safe and appropriate option.

Recommendation 35 Procedures and criteria for applying for Disabled Facilities Grants should be revised to tackle inconsistencies, reduce bureaucracy and reduce the hidden costs to carers.

Recommendation 36 Department for Social Development and the NI Housing Executive should establish mechanisms to ensure the increased use of floating support linked to an individual's needs rather than overly relying on accommodation based schemes.

OBJECTIVE 7	**To secure improvements in the mental and physical health of people with a learning disability through developing access to high quality health services that are as locally based as possible and responsive to the particular needs of people with a learning disability.**

Recommendation 37	The Department of Health, Social Services and Public Safety should produce a Regional Framework for Health Improvement of people with a learning disability providing clear direction including targets and timescales. Each HSS Board should review their Health Improvement Plans to ensure that they translate the regional framework at a local level to support improved health outcomes for children, men and women with a learning disability.
Recommendation 38	All generic health strategies, published at Department, Board and Trust level, should make specific reference to the needs of and impact upon people with a learning disability.
Recommendation 39	By December 2009 resources should be made available from within primary care to appoint within primary care a Health Facilitator for each 110- 120,000 population.
Recommendation 40	By December 2008 a Health Action Plan will be developed, as a part of the Person Centred Planning process, which is to be set in place for all those with a learning disability in contact with health and social services agencies.
Recommendation 41	With immediate effect each general practice facility and acute general hospital within Northern Ireland should have clear and formalised arrangements in place to facilitate equity of access to services for people with a learning disability.
Recommendation 42	Each general practice should establish robust medical records and health data about people with a learning disability on their practice register.
Recommendation 43	With immediate effect each general practice should have an identified link person within their local Community Learning Disability Team with whom they work collaboratively to facilitate better access for people with learning disability within primary care settings.
Recommendation 44	Equipment and wheelchair provision budgets should be increased to meet significant additional demand. This will require an increase of the proportion available to people with a learning disability.
Recommendation 45	As a matter of urgency the Department of Health, Social Services and Public Safety should consult with all 4 Health and Social Services Boards about their present and future plans for specialist assessment and treatment services for men and women with a severe learning disability with a view to greater sharing of existing and planned resources and the development of new forms of community based services.
Recommendation 46	By the end of the Review period people with high levels of adaptive functioning/mild learning disability who require therapeutic intervention as a result of mental health problems should be able to access mainstream mental health services. Support from dedicated learning disability services should be available if required.
Recommendation 47	Community based assessment and treatment services should be developed on an incremental basis to provide assessment and treatment of men and women with a learning disability who have specific mental health needs and/or challenging behaviours. The community based assessment and treatment services will

encompass behaviour support expertise that will provide outreach to individuals, families and community services and short-term intensive treatment to those within a residential facility which may be approved to treat people under mental health legislation.

Recommendation 48 As a consequence of the other mechanisms being recommended the Department of Health, Social Services and Public Safety should establish a regional plan that sets targets for the reallocation of existing resources and the securing of additional resources to enable the community services to be established.

Recommendation 49 Some people with a learning disability are at increased risk of recurrent severe challenging behaviours and/or mental illness. Health and Social Services Trusts should ensure that protocols are agreed so that a proactive approach can be taken to systematic intervention should there be signs of recurrence.

Recommendation 50 By December 2006 the Department of Health, Social Services and Public Safety should produce in partnership with service providers regional guidelines on the management of challenging behaviours within services.

OBJECTIVE 8 To ensure that men and women with a learning disability are supported to age well in their neighbourhoods.

Recommendation 51 The Department of Health, Social Services and Public Safety should review funding allocations to ensure that the projected increase in numbers of older people with a learning disability is reflected in the allocations to the learning disability programme. This shift will take cognisance of the fact that people with a learning disability may experience the effects of ageing at an earlier age.

Recommendation 52 The Department of Health, Social Services and Public Safety and Health and Social Services Boards should produce a strategic plan to address current deficiencies in services and future service provision for older people with a learning disability and their families.

Recommendation 53 Arrangements should be developed to enable people with a learning disability who have dementia to access support and expertise from mainstream dementia services. This will include mechanisms to provide a skills boost between dementia services and dedicated learning disability services.

OBJECTIVE 9 To enable people with a learning disability to have as much control as possible through developing person centred approaches in services and ensuring wider access to advocacy and Direct Payments.

Recommendation 54 By 1 January 2009 the opportunity to have a PCP should be in place for all persons with a learning disability who are in contact with HPSS agencies. From 2006 priority should be given to:

- developing Family Support Plans based on person centred principles that cross disciplines and agencies
- developing an Early Intervention Plan for children at the point of diagnosis

- ensuring that all young people with a learning disability have an effective Transitions Plan based on PCP principles in place from 14 years of age

- ensuring that all persons living with a sole family carer and/or those aged over 50 years have been offered the opportunity to have a Futures Plan agreed based on PCP principles. In addition a plan for meeting the needs of carers should be prepared. This invitation should be re-issued to family carers and the person they care for on a regular basis and no less than every 3 years.

Recommendation 55 The use of Direct Payments should be widely promoted and additional revenue monies of up to £300,000 per annum over the next 3 years ear-marked by the Department of Health, Social Services and Public Safety for the development of increased uptake of Direct Payments.

Recommendation 56 An independent advocacy service should be in place for each area serving a population of 100,000 – 120,000. A Regional Forum for People with a Learning Disability should be established with representatives drawn from local advocacy services. Both initiatives should be grant-aided through Office of the First Minister and Deputy First Minister (OFMDFM), so that they can cover all services and not just those provided by the Department of Health, Social Services and Public Safety.

Recommendation 57 A commissioning requirement of any service that includes people with a learning disability must be the evidence from providers across departments and agencies of how information will be provided in an accessible format appropriate to the needs of the individuals being supported.

Recommendation 58 Health and Social Services Boards should be required, within a regionally agreed framework, to establish mechanisms in partnership with their service providers for monitoring the degree to which Person Centred Planning is appropriately implemented and delivers on positive personal outcomes for individuals with a learning disability.

Recommendation 59 The Health and Personal Social Services Regulation and Improvement Authority should include measurement in the standards against which learning disability services are inspected of the processes used in service delivery to secure positive personal outcomes.

Recommendation 60 A commissioned programme of research and service evaluation to support the implementation of the Equal Lives Review should be established in collaboration with the Research and Development Office.

OBJECTIVE 10 **To ensure that health and social services staff are confident and competent in working with people with a learning disability.**

OBJECTIVE 11 **To ensure that staff in other settings develop their understanding and awareness of learning disability issues and the implications for their services.**

Recommendation 61 HSS Boards and Trusts should agree the role, composition, configuration and functions of Community Learning Disability Teams in light of the proposals in the Equal Lives Review by December 2006.

Recommendation 62 By April 2007 a regional workforce development strategy should be produced in partnership with employers from the independent and statutory sectors that identifies the workforce implications of the Equal Lives Review and sets out a clear strategy for addressing them.

Recommendation 63 All service providers who receive funding from the Department of Health, Social Services and Public Safety Training Support Programme should be required to evidence how people with a learning disability have been involved in the design, delivery and/or evaluation of training programmes provided on learning disability specific issues.

Recommendation 64 Service providers who receive Training Support Programme funding should be required to demonstrate that arrangements are in place to open access to the training provision to family carers, volunteers and people with a learning disability where possible.

Recommendation 65 Funding should be allocated to the Review Implementation Steering Committee for a Leadership Innovation Fund to which all agencies and professions might apply, designed to promote interagency initiatives that develop the leadership and managerial capacity in organisations to deliver on the new vision in the Equal Lives Review.

Recommendation 66 From 1 January 2007 all new Direct Support Workers in learning disability services should be required to meet the Northern Ireland Social Care Council standards on induction and foundation within the first year of appointment. It is anticipated that this will normally be evidenced by completion of assessment to LDAF standards and be subject to inspection by the Health and Personal Social Services Regulation and Improvement Authority.

Recommendation 67 All generically trained health and social services professionals (medicine, Allied Health Professionals, nursing, social work) should receive at a minimum awareness raising training on learning disability.

Recommendation 68 A publicity strategy should be developed and implemented that promotes the positive factors of working with people with a learning disability and encourages greater participation in volunteering and community service.

Recommendation 69 Department of Education, Department for Social Development and Department for Employment and Learning should develop measures to encourage awareness raising and improved training on learning disability amongst agencies that they fund to support equity of access by people with a learning disability to their provision. These measures should include the development of joint training opportunities with health and social services agencies.

OBJECTIVE 12 To promote improved joint working across sectors and settings in order to ensure that the quality of lives of people with a learning disability are improved and that the Equal Lives values and objectives are achieved.

Recommendation 70 An Interdepartmental Steering Committee should be established by January 2006 to promote joint working and oversee the implementation of the Equal Lives Review recommendations.

Recommendation 71 An Implementation Support Team should be established by November 2005 to support work being undertaken to implement the Equal Lives Review.

Recommendation 72 A Regional Forum for People with a Learning Disability should be established by January 2006.

Recommendation 73 Inter-Agency Task Groups should be established by April 2006 to drive change at a local level and produce local plans in accordance with the Equal Lives values and objectives.

Recommendation 74 Ring-fenced funding continues within Department of Health, Social Services and Public Safety and Department of Education and the potential is explored for extending this to other departments to underpin the implementation of the Equal Lives Review.

REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY (N. IRELAND)

Annex B

TERMS OF REFERENCE

1. To carry out an independent review of the effectiveness of current policy and service provision relating to mental health and learning disability, and of the Mental Health (Northern Ireland) Order 1986.

2. To take into account:

   - the need to recognise, preserve, promote and enhance the personal dignity of people with mental health needs or a learning disability and their carers;
   - the need to promote positive mental health in society;
   - relevant legislative and other requirements, particularly relating to human rights, discrimination and equality of opportunity;
   - evidence - based best practice developments in assessment, treatment and care regionally, nationally and internationally;
   - the need for collaborative working among all relevant stakeholders both within and outside the health and personal social services sector;
   - the need for comprehensive assessment, treatment and care for people with a mental health need or a learning disability who have offended or are at risk of offending; and
   - issues relating to incapacity.

3. To make recommendations regarding future policy, strategy, service priorities and legislation, to reflect the needs of users and carers.

EXPERT WORKING COMMITTEES

Annex C

FIRST WAVE

- **Social Justice and Citizenship:**

  Convenor: Bill Halliday, Equality Commission for Northern Ireland

  To consider relevant legislative and other requirements, particularly relating to human rights, discrimination and equality of opportunity; and how best to promote the social inclusion of people with a mental health problem or learning disability and their carers, taking account of employment, housing, education, social security, personal finance and other social issues.

- **Legal Issues:**

  Convenor: Master Brian Hall, Office of Care and Protection

  To include a review of the Mental Health (N Ireland) Order 1986; the Mental Health Commission; the Mental Health Review Tribunal; the procedures for the transfer of patients to and from N Ireland; issues relating to people who are not able to look after their own property and affairs as a result of a mental health problem or learning disability; and issues relating to people with a mental health problem or a learning disability who are in contact with the criminal justice system.

- **Learning Disability:**

  Convenor: Siobhan Bogues, Manager, ARC (NI)

  To review policy and services for children and adults with learning disability.

- **Adult Mental Health:**

  Convenor: Professor Roy McClelland, Deputy Chair of the Review

  To include consideration of primary care provision, acute services, rehabilitation and community care for adults with a mental health problem.

SECOND WAVE

- **Mental Health Promotion:**

  Convenor: Professor Alan Ferguson, Chief Executive, NI Association for Mental Health

  To include consideration of how best to promote positive mental health in society, with particular reference to the impact of the recently-published Mental Health Promotion Strategy, and how best to meet the needs of people at risk of suicide.

- **Child and Adolescent Mental Health:**

  Convenor: Moira Davren, Royal College of Nursing

  To include consideration of primary care provision, acute services, rehabilitation and community care for children and adolescents.

- **Dementia and Mental Health Issues of Older People:**

  Convenor: Nevin Ringland, Chief Executive, PRAXIS Care Group

  To include consideration of primary care provision, acute services, rehabilitation and community care for older people with dementia or a mental health problem.

- **Alcohol and Substance Misuse:**

  Convenor: Dr Diana Patterson, Shaftesbury Square Hospital

  To include consideration of the links between mental health and alcohol and substance misuse, and the provision of the most appropriate assessment, treatment and care for those involved.

- **Forensic Services:**

  Convenor: Dr Fred Browne, Chair, Northern Ireland Division, Royal College of Psychiatrists

  To consider the assessment, care and treatment of people with a categorical mental illness, severe personality disorder or who engage in dangerous or persistently challenging, aggressive behaviour, and who may be in contact with the criminal justice system.

- **Needs and Resources:**

  Convenor: Glenn Houston, Chief Executive, Craigavon and Banbridge Health and Social Services Trust

  To support other working committees in assessing the financial implications of their recommendations.

THE REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY (NORTHERN IRELAND)

COMMITTEE STRUCTURE

GLOSSARY

Annex D

Allied Health Professionals	These include physiotherapists, speech and language therapists, occupational therapists, podiatrists, radiographers, and dieticians
Challenging Behaviour	When someone is behaving in a way that might cause harm to themselves or to other people. Services are challenged to find a way of managing the behaviour so the chance of harm is reduced
Citizenship	People with a learning disability are treated as equal citizens
Domiciliary Support	Support provided to a person in their own home
Empowerment	People with a learning disability are supported to take a full part in decisions affecting their lives
Expert Working Committee	A group including carers, men and women with a learning disability and staff who were asked by the Review to find out what needs to be done to make things better for people in the future
Forensic Issues	Issues for people with a learning disability who commit offences whether or not they come in contact with the criminal justice system or who are at risk of offending
Inter-agency	Links between organisations that have responsibility for either the commissioning and/or the delivery of services
Intra-agency	Subsections within the one agency working together more closely
Inter-departmental[1]	Government departments working together
Inter-disciplinary/ Inter-professional	Staff in services from different professions working together with an individual service user, or in the planning and delivery of services to groups of service users and carers. E.g. nurses, social workers, teachers, allied health professionals, clinical psychologists and psychiatrists
Inter-sectoral	Working together between the statutory sector (bodies that are directly managed by government) and the independent sector (voluntary organisations, community groups and the private sector)
Legislative	To do with the law
Mainstream	Generally available to everyone in the community

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[1] Other terms are sometimes substituted such as cross departmental or pan–agency working. These are taken to mean the same as inter as in inter-departmental

Multi- Agency Centres	A one-stop shop for children, their families and the staff who support them where staff from a range of organisations are in the one place to offer support, advice and information
Prevalence	Working out how many people in a community have a learning disability
Primary Care Services	Health and social services that are generally available directly to everyone e.g. dentist, GPs
Revenue Allocations	Money allocated for daily costs like staff salaries or rent
Sensory Impairments	A loss of sight and/or hearing
Social Inclusion	When people with a learning disability feel part of the community that they live in
Supported Employment	Helps people with a disability to get a job by giving the right help and support
Terminology	The names we use for different things
Transition	A time in people's lives when big changes are happening, like leaving school or getting old

Abbreviations

ARC	Association for Real Change
DCAL	Department of Culture, Arts and Leisure
DE	Department of Education
DEL	Department for Employment and Learning
DHSSPS	Department of Health, Social Services and Public Safety
DRD	Department for Regional Development
DSD	Department for Social Development
EHSSB	Eastern Health and Social Services Board
FE	Further Education
HPSSRIA	Health and Personal Social Services Regulation and Improvement Authority
HPSS	Health and Personal Social Services
HSS	Health and Social Services
LDAF	Learning Disability Award Framework
NHSSB	Northern Health and Social Services Board

NICVA	Northern Ireland Council for Voluntary Action
NISCC	Northern Ireland Social Care Council
NVQ	National Vocational Qualification
OFMDFM	Office of First Minister and Deputy First Minister
PCP	Person Centred Planning
PSS	Personal Social Services
RPA	Review of Public Administration
SHSSB	Southern Health and Social Services Board
SLD	Severe Learning Disability
TSP	Training Support Programme
UN	United Nations
WHSSB	Western Health and Social Services Board

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COMPOSITION OF EQUAL LIVES REVIEW WORKING GROUPS

Annex F

Learning Disability Working Committee

Andrew Bailey	PSNI
David Bamford	Chair Mental Health and Learning Disability Review
Siobhan Bogues	ARC
Maurice Devine	Down Lisburn Health and Social Services Trust
Kieran Downey	Sperrin Lakeland Trust
John Hunter	Department of Education Northern Ireland
Mary Lunny	Parent
Agnes Lunny	Positive Futures
Roy McConkey	University of Ulster at Jordanstown/ Eastern Health and Social Services Board
John McEleney	Foyle HSS Trust
Catherine McGuigan	Equal Lives Group
Joan McGuinness	Longstone Hospital
Colin McMinn	DHSSPS
Brendan Mullen	Ulster Community & Hospitals HSS Trust
Marian Nicholas	Parent
Maureen Piggot	MENCAP
Moira Scanlon	Occupational Therapist
Oliver Shanks	Psychiatrist
Eileen Sherrard	Clinical Psychologist
Tom Smith	Southern Health and Social Services Board
Miriam Somerville	North & West Belfast HSS Trust
Nigel Stratton	Homefirst Community Trust

Equal Lives Group

Orlagh	Cassidy
Joe	Coyle
Hilary	Gammon
Alan	Henry
Gerald	Maguire
John Paul	McCusker
Catherine	McGuigan
Cathy	McKillop
John	Mullan
Patrick	Hill
Nigel	Reid
Trevor	Rhodie
Nora	Smith

Advisers to Equal Lives Group

Paul	Roberts
Siobhan	Wylie
Judith	Skates (secretary)

Carers Advisory Group

Sam	Bell
Anne	Blake
Colm	Callon
Briedge	Campbell
Derek	Doherty
Sharon	Doherty
Mary	Duffin
Maureen	Gribben
Carol	Ince
Colette	Jones

Siobhan	Lappin
Mary	Lunny
Anne	Mallon
Valerie	Martin
Pat	McAlister
Teresa	McDonagh
Nuala	McGarry
Seana	McQuade
Cowan	Reid

Accommodation and Support Task Group

John Black	DHSSPS
Tony Brady	Carer
Agnes Lunny	Positive Futures
John Mc Cart	North & West Belfast HSS Trust
Roy Mc Conkey	University of Ulster at Jordanstown/ Eastern Health and Social Services Board
Colin Mc Minn	DHSSPS
Brian O' Kane	Supporting People
Tom Smith	Southern Health & Social Services Board

Ageing Issues Task Group

Kate Comiskey	Blair Lodge
Chris Conliffe	Scientist Practitioner
Peter Deazley	DHSSPS
Margaret Maybin	Training and Practice Development Team
Janet MacPherson	North & West Belfast HSS Trust
Moira Scanlon	Craigavon & Banbridge HSS Trust
Kay Trolan	Parent
Vivienne Williamson	St Luke's Hospital

Children and Young People Task Group

Margaret Black	Northern Health and Social Services Board
Oscar Donnelly	North & West Belfast HSS Trust
Pauline Ferguson	Positive Futures
Hilary Harrison	DHSSPS
Nan Hill	South & East Belfast HSS Trust
John Hunter	Department of Education Northern Ireland
Goretti Horgan	Parent
Mandy Irvine	North & West Belfast HSS Trust
Rosemary Kilpatrick	Institute of Child Care Research
Mary Lunny	Parent
Pat McAlister	Parent
Alison McCullough	South & East Belfast HSS Trust
Aidan Murray	Eastern Health and Social Services Board
Michael Palframan	Barnardos
Maureen Piggot	MENCAP

Day Opportunities Task Group

Alison Anderson	Skill Northern Ireland
Liam Burns	MENCAP
Damian Cassidy	The Appleby Trust
Kieran Downey	Sperrin Lakeland Trust
Edyth Dunlop	Northern Ireland Union for Supported Employment
Ian Hayes	Service User
Brendan Linton	MENCAP
Roy Mc Conkey	University of Ulster at Jordanstown/ Eastern Health and Social Services Board
Barry Mc Menamin	MENCAP
Colin Mc Minn	DHSSPS
Eilish Rehill	FACT
Jude O'Neill	Western Health & Social Services Board

Physical Health Task Group

Owen Barr	University of Ulster at Magee
Maurice Devine	Thompson House Hospital
Sean Donnelly	Clifton Street Surgery
Lucy Finnegan	South & East Belfast HSS Trust
Therese Kane	Albert Street Healthy Living Centre
Neil Kelly	South & East Belfast HSS Trust
John McEleney	Foyle HSS Trust
Margaret Mc Elroy	Carer
Eveline Milne	Longstone Hospital

Mental Health Task Group

Owen Barr	University of Ulster at Magee
Don Bradley	Ulster Community & Hospitals HSS Trust
Petra Corr	North & West Belfast HSS Trust
Maurice Devine	Thompson House Hospital
Ian Mc Master	DHSSPS
Joan Mc Guinness	Longstone Hospital
Brendan Mullen	Ulster Community and Hospitals HSS Trust
Marion Nicholas	Parent
Oliver Shanks	Psychiatrist
Irene Sloan	Challenge
Miriam Somerville	North & West Belfast HSS Trust

LEGISLATION IN NORTHERN IRELAND

Annex
G

Most of the recent legislation in Northern Ireland has followed on from Parliamentary Bills first introduced at Westminster and this is usually done by Orders in Council. The main extant Orders (arranged by date order) affecting people with a learning disability are:

Chronically Sick and Disabled Persons (NI) Act 1978

This provides for the identification of people with a disability for the purpose of providing welfare services under the Health and Personal Social Services (NI) Orders 1972. It also provides for the laying before the NI Assembly of two reports, one on the placement of people under 65 in a hospital mainly for the care of elderly people (Section 12 report) and the other on the placement of people under 65 in premises for people over that age (section 13 report).

Mental Health (NI) Order 1986

Under this Order people with a learning disability (referred to in the Order as mental handicap/mental impairment) can be detained in hospital for assessment and treatment if they are suffering from a mental disorder, the nature and degree of which presents a substantial risk to themselves, and when failure to detain them creates a substantial likelihood of serious physical harm to themselves or others. The Order also allows for people to be received into guardianship to ensure that the person receives the care and protection he or she needs. The Order also allows steps to be taken to manage the property and affairs of people who cannot do so for themselves.

Education and Libraries Boards (NI) Order 1986 and Education (NI) Order 1996

Under these Orders, Education and Library Boards have a duty to identify and assess children in their area who have special education needs and children who they think have, or will have, special education needs. If the assessment finds that a child has special education needs, the Education and Library Board must issue a statement explaining these needs which must also detail the special arrangements being made by the Education and Library Board to meet those needs.

The 1996 Order provides a legal framework for the assessment and development of special education needs. It is accompanied by a Code of Practice on the Identification and Assessment of Special Education Needs (Department of Education for Northern Ireland, 1997), based on its equivalent developed in England and Wales (DfEE, 1994). This code provides detailed guidance on five stages of assessment.

Disabled Persons (NI) Act 1989

The Chronically Sick and Disabled Persons (NI) Act 1978 was amended by the Disabled Persons (NI) Act 1989. The 1989 Act, in addition to the provisions in the 1978 Act, requires Health and Social Services Trusts to assess young people with disabilities, at the time they leave school, for a range of welfare services as outlined in the Chronically Sick and Disabled Persons (NI) Act 1978. The Trusts are also expected to give appropriate advice about matters such as employment and further education.

Section 5 of the Disabled Persons (NI) Act 1989 requires Education and Library Boards to notify the relevant Trust at the time of the first annual review of a statement following the child's 14th birthday, or at a time of a reassessment after that birthday, whichever is earlier. This notification is required in order for Trusts to consider the young person's needs for social services after they have left school. Education and Library Boards are also required to notify the Trust between twelve and eight months before the actual date of ceasing full-time education.

The Disabled Persons (NI) Act 1989 also gives disabled people rights to representation, to assessment of their needs, and to information and counselling. The statutory provisions relating to representation are provided in Sections 1 and 2 of the 1989 Act and intended to give the same rights to disabled people in Northern Ireland as that given in Great Britain by the Disabled Persons (Services, Consultation, and Representation) Act 1986. For example, Section 2 requires Boards or Trusts to make arrangements for social services to meet the needs of disabled people, including practical assistance in the home, transport arrangements to and from home, home adaptations, holidays and help obtaining a telephone. However, ten years on, these two sections have not yet been implemented in N. Ireland.

Carers of disabled people, including those caring for disabled young people, have the right to have their ability to care taken into account (section 8) and the right to ask for an assessment of the needs of the disabled person (section 4).

Health and Personal Social Services (NI) Orders 1991 and 1994

Under these Orders, Health and Social Services Boards are responsible for assessing the health and social welfare needs of their resident population (including disabled young people and adults) and for commissioning services to meet these needs.

These Orders brought about the purchaser/provider split in the organisation of health and personal social services, with Health and Social Services Boards "purchasing" services for their resident population and HSS Trusts "providing" services, which were agreed through contracts with Health and Social Services Boards. The Trusts may in turn sub-contract with private and voluntary organisations for services.

The Children Order (NI) 1995

This Order was made in March 1995 and most of its provisions commenced in November 1996. It brings together most public and private law relating to children and establishes a new approach to services provided by Health and Social Services Trusts for children and their families.

The Children (NI) Order 1995 provides a legal framework for the provision of social care services for disabled children and their families and seeks to ensure the integration of these services. They are to be recognised as children first with the right to have their particular needs met by the provision of services.

Young people with disabilities, up to the age of 18 (or 21 in some circumstances), are included in the Order's definition of "children in need" (Article 17).

The Order defines a child as disabled if he or she is:

"blind, deaf, dumb or suffering from mental disorder of any kind or substantially or permanently handicapped by illness, injury or congenital deformity or such other disability as may be described."

The language used is archaic and may be seen as stigmatising, but it is the legal definition to be adhered to by Trusts providing services and assessing the needs of disabled children. Disabled children, as children in need, are entitled to services necessary to safeguard and promote their welfare. Trusts are required to take reasonable steps to identify children in need in their area and to assess the needs of such children.

Northern Ireland Act 1998

Section 75 of the Northern Ireland Act 1998 states:

"A public authority shall, in carrying out its functions to Northern Ireland, have due regard to the need to promote equality of opportunity-

Between persons of different religious belief, political opinion, religious group, age, marital status or sexual orientation;

Between men and women generally;

Between persons with a disability* and persons without; and

Between persons with dependants and persons without".

**Disability has the same meaning as in the Disability Discrimination Act 1995 (see below).*

Following on from Section 75, public authorities must now undertake Equality Impact Assessments. An Equality Impact Assessment (EQIA) is a thorough and systematic analysis of a policy. The purpose of carrying out an EQIA is to identify whether there are differences in the way a policy impacts upon the nine categories stipulated under Section 75 and whether these differences are adverse i.e. do they have a negative impact on any of the equality categories. If there are negative impacts then the public body must consider how these should be addressed. This may involve developing new measures to reduce the negative impact or developing new measures that more effectively promote equality of opportunity.

This Act also established the Equality Commission for Northern Ireland which subsumed the Northern Ireland Disability Council and which undertakes the same functions as the Disability Rights Commission in Great Britain.

Other UK legislation:

Three further pieces of legislation also have implication for services:

Carers Recognition and Service Act 1995

This requires HSS Trusts to undertake an assessment of carers' needs; to provide information about services and arrange means whereby their needs can be met.

Community Care Direct Payments Act 1996

This Act which is mandatory in N. Ireland from 1998, makes it possible for disabled people, including those with a learning disability, to have a Direct Payment from HSS Trusts, to pay for their community care services. The individual can use the money to buy or organise the kind of support that best suits them rather than use services provided by Trusts or other organisations on their behalf.

Disability Discrimination Act 1996

This Act aims to ensure that disabled people have equal opportunities in terms of access to employment, buildings, and goods and services. It also requires schools, colleges and universities to provide information for people with disabilities and make suitable accommodation for their needs. There was initial debate about what constituted 'services' but parliamentary challenges have led to the affirmation that services include health and social services. Under the DDA it is illegal to discriminate by any of the following:

- refusal to provide a service
- treating a person less favourably in the standard of service, or how a service is provided
- providing a service in less favourable terms (e.g. failure to provide access for disabled people).

Under the DDA disabled people are defined as follows:

- must have a physical or mental impairment
- the impairment must adversely affect the individual's ability to carry out normal daily activities
- the adverse effect must be substantial
- the adverse effect must be long term.

Under the Act the term impairment is defined as relating to the following aspects: mobility, dexterity, physical condition, continence, ability to lift, speech hearing or eyesight, cognition (memory, concentration and learning) and perception of risk. There seems little doubt that many people with a learning disability are 'disabled' under the DDA definition. It therefore follows that people with a learning disability should be protected under the DDA.

SELECTED DEFINITIONS OF LEARNING DISABILITY

Annex H

International definitions of what is known as 'learning disability' include three elements all of which must be present:

- significant impairment of intelligence that includes a reduced ability to understand new or complex information, and to learn new skills;
- deficits in social functioning or adaptive behaviour and a reduced ability to cope independently; and
- the disability started before adulthood and has a lasting effect on development.

However the precise terminology used in definitions varies and there are significant problems in operationalising these definitions so that people can be reliably and validly classed as 'learning disabled.'

Northern Ireland

In Northern Ireland there has been relative consistency in the definitions used although the terminology is not always consistent. For example, mental handicap is defined in the Mental Health (NI) Order 1986 as:

"A state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning."

(The Order also defines 'severe mental handicap' in similar terms by substituting the word 'significant' with 'severe')

However this definition omits a key feature included in all international definitions, namely that the disability or impairment is present from childhood. Moreover the term 'development of mind' is impossible to define accurately (Foundation of People with Learning Disabilities, 2001).

Great Britain

The Scottish Review of Learning Disability Services (Scottish Executive, 2001) considered it important for any definition to give an appropriate and meaningful description of the services and supports individuals may need. Hence they state:

People with learning disabilities have a significant life-long condition that started before adulthood, that affected their development and which means they need help to understand information; learn new skills; and to cope independently (p.3).

Likewise the English Review (Department of Health, 2001) gave this definition:

Learning disability includes the presence of:

- *a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with*
- *a reduced ability to cope independently (impaired social functioning)*
- *which started before adulthood with a lasting effect on development.*

European Union

The EU Monitoring and Advocacy Program of the Open Society Institute (2003) defined intellectual disability (also described as learning disability or mental retardation) as:

A lifelong condition, usually present from birth or which develops before the age of 18; is a permanent condition that is characterized by significantly lower than average intellectual ability; results in significant functional limitations in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills.

They go on to note that "a person with intellectual disability usually requires support in three or more of the following areas of major life activity: self-care, receptive and expressive communication, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency. People with intellectual disabilities generally need a combination of special, interdisciplinary or generic services, individualized support, and other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated".

United States of America

DSM-IV Diagnostic and Statistical Manual of Mental Disorders

The American Psychiatric Association in their diagnostic classification defines mental retardation as:

(a) significantly sub-average intellectual functioning: an IQ of approximately 70 or below on an individually measured administered IQ Test

(b) concurrent deficits or impairments in present adaptive functioning (i.e. the person's effectiveness in meeting the standards expected of his or her age by his or her cultural group) in at least two of the following areas: communication, self-care, home-living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety

(c) the onset is before age 18 years.

The American Association on Mental Retardation (2002) has been an international leader in defining and assessing people with 'mental retardation'. They define mental retardation as:

A disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills. This disability originates before 18 years of age.

They go on to note five assumptions that are essential to the application of this definition:

1. "Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.

2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor and behavioural factors.
3. Within an individual, limitations often co-exist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalized supports over a sustained period, the life functioning to the person with mental retardation generally will improve".

HPSS EXPENDITURE ON LEARNING DISABILITY PROGRAMME

Annex I

By Trust 2002/03

HSS Trust	Hospital £'000	Community £'000	PSS £'000	Total £'000
Armagh & Dungannon	8375	1354	6596	16325
Causeway	150	546	4565	5261
Craigavon & Banbridge		791	5204	5995
Down Lisburn		1793	10300	12093
Foyle	2908	1313	7302	11523
Green Park	698			698
Homefirst	97	2604	15826	18527
Newry & Mourne		845	5921	6766
North & West Belfast	20734	1198	11284	33216
South & East Belfast		522	9760	10282
Sperrin Lakeland		330	6922	7252
Ulster Community and Hospitals		873	7555	8428
United		85		85
TOTAL	32962	12254	91235	136451

THE REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY (NORTHERN IRELAND)

ALCOHOL
AND
SUBSTANCE
MISUSE

December 2005

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FOREWORD

The Review of Mental Health and Learning Disability consists of several interlinked reviews under one overarching title and encompasses policy, services and legislation.

The Review Steering Committee presides over the work of 10 major Expert Working Committee's, 4 of which commenced their work by April 2003 with the remaining 6 by November 2003.

In consultation with Government, we have agreed to produce our reports separately in a phased manner. This is the third report on which the Review has consulted.

As this report acknowledges, we in Northern Ireland have not experienced the levels of drug misuse seen in our neighbouring jurisdictions, but this is not a reason for complacency. Alcohol and substance misuse take a heavy toll on not only the user, but also his or her family and neighbourhood and ultimately the general population, for example, through the higher incidence of criminal activity. Diana Patterson and her Committee have brought together an impressive array of experience and evidence in producing this draft report and I wish to record my appreciation of their hard work.

All of our Committees have adopted an evidence-based approach, drawing on existing relevant information and research and, where necessary, commissioning research. Exemplars of best practice, local, national and international, are informing our reports.

We have maintained a clear vision for mental health and learning disability services in Northern Ireland. Widespread consultation with stakeholders has endorsed our vision and the strategic direction of the Review. A feature of the Review process is the contribution of service users and carers across both mental health and learning disability; their insights, advice and guidance continue to be invaluable.

Professor Roy McClelland, Deputy Chairman of the Review, and I thank all who have been involved in developing this report. An immense amount of work is in progress.

David R Bamford (Professor)
Chairman

CHAPTER 1

VISION, PRINCIPLES AND CHALLENGES

A NEW VISION FOR ALCOHOL AND SUBSTANCE MISUSE SERVICES

1.1 The Review of Mental Health and Learning Disability has a shared vision throughout. In the case of Alcohol and Substance Misuse this is:

- valuing people with alcohol and substance misuse needs, including the rights to full citizenship, equality of opportunity and self-determination;
- addressing the challenges facing people with needs in areas of alcohol and substance misuse; and
- a process of reform, renewal and modernisation of services that will make a real and meaningful difference to the lives of people with alcohol and substance misuse problems, to their carers and families.

1.2 The vision has been greatly informed by core values derived from the consultations, the submissions to the Review and the direct involvement of users and carers within the Reference Groups used during the course of this work. People with alcohol and substance misuse problems and their carers should receive services which:

- respect them as individuals – through openness in the providing of information, respect and courtesy in individual interactions with service users, true partnership and empowerment in service planning and provision – with Government, providers and the wider society each accepting their respective responsibilities; and
- demonstrate justice and fairness – resources for services should be allocated and managed according to criteria which are transparent and which demonstrate equity.

1.3 These values are underpinned by our obligations as a community under Equality and Human Rights legislation.

PRINCIPLES

1.4 The Principles for the Alcohol and Substance Misuse Framework draw on the vision and values of the Review and are as follows:

- partnership with users and carers in the development, evaluation and monitoring of services;
- partnership with users in the individual assessment process and all therapeutic interventions of care and support;
- delivery of high quality, effective therapeutic interventions, care and support;
- equity of access and provision of services, including the needs of people from minority cultures, people with disabilities, people subject to the criminal justice system;
- provision of services which are readily accessible;
- delivery of continuity of care and support for as long as is needed;
- provision of a comprehensive and co-ordinated range of services and accommodation based on individual needs;
- taking account of the needs and views of carers, where appropriate, in relation to assessment, therapeutic interventions, care and support;
- provision of comprehensive and equitable advocacy, where required or requested;
- promotion of independence, self-esteem, social interaction and social inclusion through choice of services, facilitation of self management, opportunities for employment and social activities;
- promotion of safety for service users, carers, providers and members of the public;
- provision to staff of the necessary education, training and support; and
- services subject to quality control, informed by the evidence.

1.5 Informed by these values and principles, the Review has provided a unique opportunity to address the full spectrum of issues relating to alcohol and substance misuse problems. The plans outlined in this document depend on cultural change and on investment of new resources. This involves a new sense of partnership and equality of esteem for service users, deriving from placing value on carers as equal partners in service provision, effective team working and from collaboration with and between provider groups including user provided services.

CHALLENGES

1.6 In Northern Ireland we are fortunate to live in a society in which the family continues to exist as a cohesive unit within our culture. Within the Alcohol and Substance Misuse Working Committee we have acknowledged the needs of family members of those with substance dependence or misuse. We have also acknowledged the very strong, positive therapeutic input which can be delivered by family members across all of the areas of service delivery described in these sections.

1.7 Historically Northern Ireland has polarised attitudes to drinking. We have the highest levels of voluntary abstinence from alcohol in Western Europe, while having high levels of "binge" drinking and problem drinking. As citizens we should be concerned about factors which may make alcohol more generally available.

1.8 Investments in treatment opportunities for alcohol problems has not matched investment in treatment for drug problems despite the fact that much higher mortality and morbidity occur in our population from alcohol. The Review advises strengthening treatment facilities for those with alcohol problems.

1.9 Modern alcohol treatment starts within the community and the voluntary and community sector has an obvious role in this regard. Self-help groups such as Alcoholics Anonymous and Women for Sobriety are also of great importance in an individual's journey to the alcohol intervention services.

1.10 The effect of "the Troubles" on the drug scene in Northern Ireland has been to protect us from the higher rates of heroin use and injecting drug use experienced by our neighbours in Great Britain and Ireland. All illicit substances tend to be used less frequently in Northern Ireland than in our near neighbours, but the levels of heroin use and injecting drug use specifically are strikingly low, despite moderate increases over the past few years. These factors are considered in detail in Chapter 2. The interested reader is also referred to the Health Promotion Agency website www.DrugsAlcohol.info for more comprehensive data.

1.11 This is the first time that the issue of Harm Reduction is described in detail in a Review of Drug Treatment in Northern Ireland. Substitute Prescribing has been implemented in Northern Ireland since 1 March 2004. This form of opiate prescribing attempts to steer the injecting drug user away from the illicit drug market and also attempts to persuade him to use oral drugs rather than indulge in the dangerous behaviour of injecting drug use.

1.12 The principle of Harm Reduction accepts that some people are not ready to move towards abstinence although, for most people, eventual abstinence from the substance of addiction will be their ultimate aim.

1.13 Twenty years ago almost all treatment for alcohol problems was delivered within inpatient residential settings. Over time it has become clear that considerable gains can be achieved through early intervention and that we should attempt to help people before they develop more serious problems and, in many cases, before the development of addiction to alcohol develops.

1.14 The counselling evidence makes it clear that the early interventions, the brief interventions and the opportunistic interventions all deliver highly cost effective management for people with alcohol problems. Recommendations are made regarding this in Chapter 3. A comprehensive treatment service should make provision for those who do not respond to community intervention. More intensive, costly but effective interventions should be available for this group of people.

1.15 Service users have been able to guide the Review on issues which lead to a good service and conversely to distinguish factors which lead to a perception of poor quality services. The voices of service users must guide not only in this Review of Alcohol and Substance Misuse Services, but also in the whole area of future service development for those with alcohol and substance misuse.

1.16 Experiences of service users have indicated that while there are examples of good practice in Northern Ireland, the coverage is "patchy". Some services are only available to those living in certain areas. In particular, the development of community addiction services has not proceeded uniformly across the province. This has led to a situation where certain services are not available to some individuals in Northern Ireland. In some instances this has arisen for geographic reasons, in others it has arisen because mainstream services are not resourced to meet the needs of vulnerable members of our community: the young, those with learning disability, the elderly, the socially disadvantaged and ethnic minorities.

1.17 This Review of Alcohol and Substance Misuse has focused attention on these vulnerable subgroups and on a range of issues raised by service users and carers. These include homelessness, employability of those with substance misuse and smoking within the mental health services. These concerns about the uneven spread of resources and services has led to strong recommendations regarding the equitable distribution of services for those with alcohol and substance misuse problems. Equity of access to all elements of services must be paramount and should be reflected in the commissioning process.

1.18 In the recommendations for the organisation of services for those with alcohol and substance misuse, we have borrowed heavily from the recommendations of the National Service Framework for alcohol and drugs. There should be adoption of the 4 Tier model of service delivery recommended by the Substance Misuse Advisory Service and the Models of Care document developed by the National Treatment Agency.

1.19 There should be a system of co-ordination of care for those with alcohol and substance misuse who have complex needs. The full text can be accessed at: www.nta.nhs.uk

1.20 The commissioners of services have responsibility for ensuring that mechanisms for such co-ordination are in place.

1.21 It would be impossible to conduct a Review of Alcohol and Substance Misuse Services without acknowledging the immense contribution of the non-statutory sector to service provision. This is addressed in Chapter 3.

1.22 Future service provision demands closer integration of the non-statutory sector with the statutory services, a responsibility which must fall to commissioners of services.

1.23 Recommendations made within this Review have a strong evidence base which has been carefully reviewed for the prospective reader. For each chapter, the bibliography and associated review is included in the Annexe of the same number. Because of the relevant importance of the field of counselling within the services for substance misuse, we have included a comprehensive review of counselling for alcohol and drug misuse. This is included in its full form at: www.rmhldni.gov.uk

1.24 Within the field of alcohol and substance misuse, health promotion overlaps closely with treatment provision, particularly treatments delivered at Tier 1 and 2 of our proposed service model. Such health promotion must be available to all of us as citizens and should not be targeted simply to those who have developed "a problem", but should form part of the mainstream education curriculum. Vulnerable groups of the population, including people who have learning disability, deserve greater efforts in the delivery of such education. The interested reader is guided to the Mental Health Promotion Working Committee publication: www.rmhldni.gov.uk

1.25 Concerns about poor services to people with learning disability has led us to commission an audit of people with learning disability of school leaving age, who have developed problems with alcohol or drug misuse. This work also attempts to examine the health education delivered to this population within the school curriculum. This major piece of work can be examined at: www.rmhldni.gov.uk Specific recommendations in relation to this group are provided in Chapter 9 and Annexe 9, informed by significant input from the Learning Disability Working Committee and their Mental Health Task Group.

1.26 Another vulnerable subgroup is young people. At present there are limited Tier 2 services available for this group through the voluntary field. There are currently no Tier 3 or Tier 4 services.

1.27 The provision of this important area of management for young people should be separate from the Treatment Services provided for adults.

1.28 In Chapter 8 and Annexe 8, particular recommendations are made about the commissioning of services and the nature of services which are considered necessary for young people with alcohol or drug problems.

1.29 These have been informed by the Child and Adolescent Mental Health Working Committee.

1.30 The costs of alcohol misuse to the Health Services are detailed in Chapter 2. The real cost of alcohol and drug misuse occurs to the individuals and to their families.

1.31 In this chapter it has became clear that, for the process of review, we have disaggregated the various components of substance misuse and dealt with them separately. People do not separate neatly into categories and we must ensure that the services delivered are re-integrated in nature, so that the various needs of each person are properly addressed. A holistic approach is essential in this field.

1.32 It should be noted that during the final stages of the development of this Report, a review was carried out of the current Northern Ireland Drugs and Alcohol Strategies, and the Joint Implementation model tasked with delivering the strategies' objectives. In June 2005 Professor Howard Parker published his Review Report which contained a number of comments and recommendations pertinent to this Report. The text can be viewed at www.dhsspsni.gov.uk/publications/2005/drugs-alcohol-Report-NI-review Development of a New Strategic Direction for Alcohol and Drugs in

Northern Ireland is now underway, and due notice of the issues raised in Professor Parker's report is being taken. The New Strategic Direction is to be launched in May 2006 following consultation.

MAKING IT HAPPEN

1.33 The necessary workforce to implement the recommendations of this report is described in the workforce document of the Alcohol and Substance Misuse Working Committee and is available at: www.rmhldni.gov.uk The report should be read in conjunction with other Review reports which are also available at this web address.

1.34 Several common themes have emerged and are summarised in the following recommendations.

Recommendations

1. Partnership and collaborative working should be encouraged across all sectors. Joint working and co-ordination should be encouraged among all service providers.
2. Referral pathways and protocols should be agreed across services, agencies and community/voluntary interfaces.
3. Commissioners should involve services users, carers and providers in the joint planning and commissioning of services.
4. There should be agreed service specifications, standards, staff competencies and monitoring arrangements.
5. Standardised assessment instruments should be agreed across Northern Ireland and implemented with an IT strategy.
6. Evidence based practice should be promoted.

7. Training and support must be provided for specialist and non-specialist staff. Training programmes should be multi-agency and multi-disciplinary.

8. Service planning should be based on needs assessment with resources allocated to meet identified needs.

CHAPTER 2

CURRENT POSITION

REGIONAL CO-ORDINATION

2.1 The Drugs and Alcohol Implementation Steering Group (DAISG), chaired by the Minister for Health, Social Services and Public Safety, oversees and reviews progress on the joint implementation of the *Drugs Strategy for Northern Ireland* (1999) and the *Strategy for Reducing Alcohol Related Harm* (2000), and ensures a co-ordinated approach to tackling drug and alcohol misuse. DAISG membership comprises senior representatives from the Northern Ireland Office, the Department of Education, the Department of Social Development, the Department of Employment & Learning, the Department of the Environment, the Department of Culture, Arts & Leisure, the Department of Enterprise, Trade & Investment, as well as the Health Promotion Agency, the Northern Ireland Prison Service, the Police Service of Northern Ireland, the Probation Service of Northern Ireland, HM Customs & Excise, representatives from the voluntary & community sector, the Community Addictions Team Forum, the chairs of the local Drug & Alcohol Co-ordination Teams based in the 4 Health & Social Services Board areas and the Working Group chairs. There are 6 regional Working Groups contributing to the implementation process – Education & Prevention, Treatment, Communities, Information & Research, Social Legislation and Criminal Justice. The Drugs and Alcohol Strategy Team serves as an administration and co-ordination point for drug and alcohol misuse issues.

2.2 The Treatment Working Group (TWG) is charged with looking at the co-ordination and provision of treatment services in Northern Ireland, with a view to enabling people with drug and alcohol problems to overcome them and live healthy lifestyles. Over the last 3 years, as part of its Action Plan, TWG has established, province-wide, a Counselling Service for Young People taking Drugs and Alcohol and a Dual Diagnosis Service, as well as facilitating a Needs Assessment of Addiction Services for those aged under 18 years.

2.3 At a local level, the 4 Drug & Alcohol Co-ordination Teams address substance misuse issues relevant to each Health & Social Services Board area. This structure has enabled information collection and needs assessments for the whole of the province's population.

General Adult Population

2.4 The Drug and Alcohol Information Research Unit has co-ordinated information gathering so that we have improved information at population level, as well as information about people presenting for treatment. Much of this information is collected in an anonymised fashion so that individuals cannot be identified inappropriately.

2.5 The continuous household surveys are repeated at intervals and effort and attention is given to ensure the relevance of information collected and continuity. This provides a picture of drug and alcohol use in Northern Ireland over time.

Alcohol

2.6 Northern Ireland has one of the highest levels of abstinence in Europe. This is declining in more recent years, but some 25% – 30% of adults drink very infrequently (NISRA 1998, 1999 and 2000, Health Promotion Agency Northern Ireland, 2002).

2.7 A substantial proportion of the population drinks in excess of the low risk guidelines of 21 units per week for men and 14 units per week for women. In 1999, 22% of males and 9% of females consumed above those levels.

2.8 In the 1999 continuous household survey, adults from higher income households were more likely to drink alcohol. More separated and divorced people took alcohol than others while those who were widowed were least likely to drink. The effect of marital status was greater for women than for men. Significantly more Catholics (76%) than Protestants (67%) drank and this was true for both sexes.

2.9 Some 56% of the sample drank alcohol at least once a week. One in 10 took alcohol almost every day. Twice as many men (15%) as women (7%) drank daily. Daily drinking was more common in older people of both sexes with 25% of men aged 45 – 59 and 23% of men aged 60 – 75 drinking almost every day.

2.10 Most (71%) younger men (aged 18 – 44) drank once a week. There was a steep rise in drinking over Friday and Saturday nights.

2.11 The main drink of choice for men was beer, lager, cider or stout (77%), followed by wine (27%) and spirits (26%). For women the main choice was wine (50%), followed by spirits (42%) then beer, lager, cider and stout (23%). The main setting for drinking was in people's own homes (55%) followed by the pub (33%), although younger men were more likely to drink in a pub (65%).

2.12 Binge drinking was defined as more than 10 units in any 1 session of a sample of drinkers asked to keep a drink diary, 48% of drinking men showed a pattern of binge drinking with at least 1 binge each week. This pattern was more common in the semi-skilled or unskilled manual groups. It was most likely to occur on a Saturday in people of both sexes. This pattern of binge drinking has given rise to a degree of concern as it is associated with more health risks than more steady, continuous drinking.

Drug Use in the General Population

2.13 Drug use in Ireland and in Northern Ireland is well described in the bulletin of that name, published in March 2004. The lifetime prevalence of illegal drug use varies from 11% - 29% across Health and Social Services Board areas in Northern Ireland. Overall some 20% of subjects surveyed had lifetime prevalence of illegal drug use.

2.14 This was higher amongst men (27% of men compared to 14% of women had ever used an illegal drug) and it was higher among young people (31%) compared to the older age groups where only 12% of people had used an illegal substance. Older people and women were more likely to misuse sedatives, tranquillisers and anti-depressants.

2.15 This survey was carried out in respondents aged 15 – 64 in households across Northern Ireland. It was weighted by gender, age and health board area.

2.16 20% of the population who had taken an illegal drug. 6% had taken an illegal drug in the previous year and 3% had taken an illegal drug in the previous month.

2.17 Cannabis was the most frequently misused illegal drug with 17% of the population reporting having ever taken this drug and 3% reporting use in the previous month.

2.18 Ecstasy had a lifetime prevalence of 6% in the population studied, Poppers 6%, Amphetamines 4%, LSD 5%, Magic Mushrooms 4%, Solvents 3% and Cocaine 2%. Less than 1% of the sample had used Anabolic Steroids and 0.2% of the sample had ever tried heroin.

2.19 Tobacco use in this population had a 60% lifetime prevalence with 41% having smoked in the previous year. There was a slight male excess of cigarette smoking and a slight excess among young adults compared to older adults.

Problem Heroin Use

2.20 A capture/re-capture study was carried out on the population of Northern Ireland by McElrath in 2002. This methodology is borrowed from Biology and is the method of choice for estimating sample sizes of "hidden" populations. This study estimated that there were between 695 and 1018 problem heroin users in Northern Ireland during the 12 month period 1 November 2000 – 31 October 2001. The estimated point prevalence was 828 problem users. During the same period some 361 individuals who were using heroin sought treatment or attended a drug service for at least 1 day. Between 48% - 64% of the sample had not been in treatment during the previous 12 months.

Treatment Data

2.21 The Drug and Alcohol Information Unit has co-ordinated the collection of material by the Drug Misuse Database. This should reflect those individuals who presented for treatment for drug misuse problems (excluding alcohol) and who consented their information being included on the Drug Misuse Database. 1409 individuals presented for treatment during the period April 2003 – March 2004. This showed an increase of 4% over the previous year. The majority (76%) of those seeking treatment were male. 37% were in their 20's and 34% were under the age of 20 years.

2.22 As in the general population, cannabis was the most commonly reported main drug of misuse (52% of clients). Heroin use was reported by 12% of treatment attendees.

2.23 This compared with 16% who had attended with heroin misuse in 2002 – 2003. 73% of those presenting with heroin misuse had had previous treatment.

2.24 Injecting declined from 21% in 2002 to 18% in 2003. Cocaine use remained steady at 5% in those seeking treatment.

Addicts Index

2.25 In Northern Ireland doctors have a statutory duty to make a notification to the Chief Medical Officer if they attend someone who they believe to be addicted to a notifiable range of drugs. This information is held in an anonymised fashion by the Chief Medical Officer. There were 241 persons registered on the Addicts Index at 31 December 2003, a reduction of 55 from 296 persons registered a year previously. 73% of persons registered on the Index were male, 35% were in their 20's while 28% were aged 30 – 35.

2.26 Heroin was the most frequently reported notifiable drug, used by 72% of those seen by a doctor for drug misuse. The next most commonly reported drugs were methadone (17%) and cocaine (10%).

2.27 For 29% of registered addicts, their injecting behaviour was unknown. Of the remainder some 57% were currently injecting.

Unlinked Anonymised Prevalence Monitoring Programme

2.28 This unlinked anonymised programme survey of injecting drug users monitors HIV, hepatitis B and hepatitis C infection levels in those presenting to specialist services. 130 samples were returned from specialist agencies across Northern Ireland in 2003. 23% were aged under 25 and 73% of the sample were male. These people self-reported that they had injected drugs during the previous year. 88% had used opiates and 37% had used stimulant drugs. Heroin was the most common drug (93%) reported by those who had injected in the few weeks prior to the survey.

2.29 17% of the sample of IV drug users had antibodies to hepatitis C and most of these people were aware of their infection. 2% of the sample had antibodies to hepatitis B core antigen. This is a much lower prevalence than that found in any region of England or Wales. 49% reported having received 1 or more doses of the vaccination against hepatitis B. This is a higher proportion than in a similar sample in Wales, but not higher than several regions in England.

2.30 HIV infection occurred in less than 1% in the injecting drug users who took part in this survey. Most participants reported that they had had a confidential voluntary test for HIV at some point.

2.31 44% of those who reported injecting in the previous 4 weeks also reported direct sharing of needles and syringes. This was higher than the percentages reporting this behaviour in England and Wales. 90% of the sample reported that they had used the needle and syringe exchange scheme. Just under half had ever been to prison and 1 in 5 of the sample reported injecting in prison.

Harm Reduction Services

2.32 Information has been collected by the Drug and Alcohol Information Unit regarding activity in the Needle and Syringe Scheme in Northern Ireland. This programme is delivered by a small number of participating pharmacies.

2.33 Some 7508 visits were made to participating pharmacies during the spell 1 April 2003 – 31 March 2004.

2.34 This was a 24% increase on the previous year's activity. During the same spell returns fell from 61% to 59%. 82,731 syringes and 82,589 needles were issued. 80% of visits were made by male clients and 52% were by clients aged 30 or under. 35% of visits were by clients reporting themselves as new clients. On 17 visits (0.2%), clients reported that they had shared needles.

Statutory Addiction Services Provision

2.35 An audit was carried out on the Statutory Addiction Services from April 2001 – March 2002 (Kenny, 2003). The purpose was to provide a stock take of existing services, an analysis of relationships between the Community Addiction Teams and other services including primary care and the non-statutory sector and a prospective 3 months analysis across each Health and Social Services Board.

2.36 The population served was considered to be that aged over 18 in Northern Ireland. This comprised 1,232,830 people or 73% of the overall population in Northern Ireland. This population is served by 6 Community Addiction Teams with population ranges from 1 14,563 (Ulster and Community Hospital Trust Addiction Service) to 315,487 (Northern Health and Social Services Board Addiction Service). The geographic area covered ranges from 13,643 hectares (Belfast Addiction Service) to 484,081 hectares (Western Health and Social Services Board Addiction Service).

2.37 The annual core funded spend for drug and alcohol statutory services for the period of the study was £4,199,070. The overall total funded budget (including core and non-core services) was £5,853,420. Treasury allocation to implement the drug strategy within treatment services comprised £1,654,350 for a year. The total spend per head on drugs and alcohol treatment was £3.40 per year.

2.38 In a year in Northern Ireland 920 people received inpatient treatment in hospital or at one of the residential services in Northlands, Londonderry and Carlisle House, Belfast. In total there are 70 inpatient beds available to the population aged over 18 years. 64% of those treated were male and the largest age group represented was that aged 36 – 45 years. Alcohol was the main reason for admission in the majority (69%). Drugs comprised the reason for admission in 26% of admissions and both problems were present in 3% of admissions. Dual diagnosis, the co-occurrence of addiction and serious mental illness, was present in 1.7% of those admitted for alcohol or drug problems.

2.39 During the year audited, there were 7,749 referrals to the Community Addiction Services. 70% of referrals were male. Alcohol was the cause of referral in 72% of cases, drugs in 23% and both problems in 3%.

2.40 Dual diagnosis was the reason for referral in 2% of cases. General practitioners were the main source of referrals, referring 47% of the Community Addiction Team cases. Four teams had 22,612 face-to-face contacts over the course of the year in question. There were 58 Addiction Clinics delivered weekly in 40 different locations. These provided a range of interventions from abstinence support through to Substitute Prescribing. Of note is the fact that there was a 15% increase in referral rates to the Community Addiction Teams over the last 3 years. There is also increased collaboration with the non-statutory sector.

2.41 This is very positive, but produces increased demands on already overstretched statutory provision.

2.42 Kenny (2003) recommended that there should be a more strategic and proactive approach to managing key interfaces which he identified as the acute general hospitals, adolescent services, criminal justice services, services for the older age group and general mental health services. The report suggested that the existing arrangements were “ad hoc”.

2.43 Kenny (2003) further recommended that a unified approach should be adopted to outcome measurements which would require IT investment and additional resources. This report also made reference to the Telford Workforce Analysis which reported serious under provision across the statutory sector addiction services at inpatient and community addiction team levels. The report stated that this impacted on the time treatment units were able to operate and on the range of services provided.

Costs

2.44 The costs of alcohol related harm in Northern Ireland are substantial and were estimated at £777.5 million in 1997/1998 in Reducing Alcohol Related Harm in Northern Ireland, (DHSS, 1999).

2.45 The major part of the costs accruing to alcohol lies within the social cost to industry from days lost, premature deaths and unemployment. The direct costs to the Health and Personal Social Services were estimated at £34.3 million of which £3.5 million was accrued by the psychiatric hospitals in terms of occupied bed days, £8.8 million was accrued by the general hospitals in terms of occupied bed days and £12.8 million was the direct cost attributed to general practice for alcohol related harm.

Cost-Effectiveness of Treatment

2.46 Holder (1992) examined the total health care costs of 3729 alcoholic subjects in a 14 year follow-up study. This showed that once treatment was started, the total health care costs for patients declined by 23% from their highest pre-treatment levels. Holder's study showed alcoholism treatment can reduce the overall medical costs in an alcoholic population. There are likely to be substantial cost benefits to the National Health Service in Northern Ireland from investment in alcohol treatments.

2.47 The National Treatment Outcome Research Study (2001) found that for every £1 spent on treating drug users, £3 was saved in the cost of crime.

2.48 This figure has been upgraded within the same research project and findings published in 2004 suggest that between £9 and £18 are saved in terms of cost to the criminal justice system for every £1 spent on treatment in England and Wales. Similar savings within the criminal justice system would be expected in Northern Ireland with investment in treatment.

Populations with Specific Needs

2.49 Young People: A secondary analysis of Drug and Alcohol Use Surveys (October 2002) suggests that 24.5% of children aged 12 – 16 have ever used drugs. The frequency increases with age. This has increased over time so that the Health Behaviour in Schoolchildren Survey 1992 showed increases from 15.8% in 1992 to 33% in 2000. 5.6% of children were currently using substances in 1992 and 24.7% were currently using substances in 2000.

Alcohol is still the most commonly used drug. Half the sample stated that they had had alcohol at some time. Almost ⅓ of children reported regular use.

2.50 Cigarette use was the next most common of the substances with over 10% of pupils reporting some regular smoking.

2.51 In terms of drug use, solvent use only was the most common pattern (8.9%) and cannabis use alone occurred in 4.1% of pupils. Solvents and cannabis together occurred in 1.6% of pupils. Other drug use was rare in this group.

2.52 People with Learning Disability: Information on this population is sparse and the Alcohol and Substance Misuse Working Group commissioned an audit on the adult learning disability population across 4 Trust areas of Northern Ireland. This is described in www.rmhldni.gov.uk The prevalence of substance misuse in adults aged 18+ with a learning disability, and known to such services, was 0.8% of the total adult learning disability population across the 4 areas. This is somewhat lower than the prevalence of substance misuse in the general population of the same age. Those with learning disability were more likely to have borderline to mild learning disability than moderate. One third had a co-existing mental health problem and over ⅔ lived in independently or in supported living accommodation. Alcohol was misused by all of the participants with a small number also misusing a combination of cannabis, ecstasy, prescribed medications and amphetamines. These subjects reported that they used substances for social reasons (“to fit in” with their peers) and perceived psychological benefits from the substances.

2.53 Older People: With increasing age the effects of alcohol related disability may become more evident. Older people are more likely than younger people to drink daily. Some 17% of those aged 60 – 75 years drink daily in Northern Ireland. Older men in Northern Ireland are more likely to prefer wine or spirits rather than the beer, lager, cider or stout preferred by younger men. Older women in Northern Ireland are more likely to drink spirits than their younger counterparts.

2.54 The Homeless Population: Substance misuse is a significant issue among homeless people in terms of both prevalence of use and dependence on substances. Substance use is a factor in becoming homeless and in remaining homeless. (Drug and Alcohol Information Research Unit, September 2004).

Recommendations

9. A unified approach should be adopted in relation to outcome measures in people with substance misuse problems.

10. There should be a strategic approach to management at key interfaces for the substance misuse services. These include Acute General Hospitals, Adolescent Services, Criminal Justice Service, Services for the Older Age Group, Mental Health Services and Maternity Services.

11. Benchmarking should be enhanced to enable commissioners to address resource issues effectively.

CHAPTER 3

VOLUNTARY AND COMMUNITY ORGANISATIONS (VCO)

BACKGROUND

3.1 In the 1970's hospital based statutory provision and the large self-help group Alcoholics Anonymous (Annexe 3) were the main sources for help for people with alcohol dependency in the province. In 1988 DHSS presented a five-year strategy document for the prevention of alcohol misuse in Northern Ireland. This group relied mainly on a Northern Ireland community health study known as the Blaney and McKenzie Report (1978) which estimated that there were 40,000 problem drinkers (4% of the adult population) of whom 11,300 could be classified as "alcoholics". In 1988 provision of treatment was scant. This consisted of beds in 6 psychiatric hospitals with the treatment based on a medical model.

3.2 It was at this time that 2 major voluntary organisations in Northern Ireland expanded and developed. Both of these organisations were community based and included the training of voluntary counsellors who would in turn deliver a counselling service to those people who sought help, either by self referring, or being referred by primary care workers. A number of other church based or temperance movement voluntary agencies existed and were characterised by education and guidance.

3.3 During the 1980's changes had occurred in thinking and a wider range of individuals were considered suitable for intervention and help. Research suggested that hospital treatment was not necessary or relevant for many of the people who could benefit from intervention. This became known as 'broadening the base' (Institute of Medicine, 1990). With this shift in ideas came a small increase in voluntary agencies in the province who dealt with people with addiction problems of varying levels. By 1990 a number of non-statutory agencies existed, some funded by churches or temperance movements. Some were staffed by ex-alcohol misusers and others staffed by trained generic counsellors.

3.4 By the early 1990's in the UK the voluntary and community contribution and value was quite well established. Much had been written and researched about how best to deal with the large number of people who now qualified for intervention. Statutory services had moved largely to community based services. In 1996/7 the Continuous Household Survey (Northern Ireland) indicated that 132,000 men and 52,000 women were drinking above recommended levels, that there were increases in the reporting of problems amongst women, in young people, and binge drinking was noted as a worrying problem.

3.5 During the latter part of the 1990's focus began on populations which were hard to engage e.g. injecting drug users (see Chapter 7), and those in the criminal justice system (see Chapter 11). This led to the development of outreach and advocacy services.

3.6 From 2001 the alcohol and drug strategies were implemented together as the Joint Implementation Model (JIM) and increasingly voluntary and community agencies were dealing with clients who had an alcohol and/or drug problem or multiple substance misuse. From the mid/late 1990's an increased number of training courses were available for people who wanted to train as addiction counsellors. However there was an impermanency surrounding many of the projects. When JIM was launched, many projects delivered by the voluntary and community sector benefited from the funding. This resulted in an increase of small projects, non-recurrently funded in the community. In 2004 the Drug Misuse Database (DMD) includes data on 15 community and voluntary organisations delivering, on multiple sites, services, some of which are in partnership with statutory services. Undoubtedly there are many more who are not contributing to the drug misuse database. It would be desirable to have a comprehensive list of services.

3.7 There should be encouragement of proposed projects which address identified gaps in existing service provision. This could involve any tier of the models of care document (Annexe 4).

The Contribution of the Voluntary and Community Organisations (VCO)

3.8 For many people, the self-help organisations represent the first, and perhaps, only source of advice and support. The majority of these do not accept funding for their services. Various self-help groups cater for those with specific issues in addiction, and their families and friends. Information about local meetings can usually be accessed through the Community Addiction Teams.

3.9 Within the models of care framework (NTA) (Annexe 4) it is likely that the voluntary and community organisations can contribute to tiers 1,2,3 and possibly 4. This framework should be clearly understood and goals set according to the tier being addressed. For each tier it is necessary to:

- have specific descriptions of the model of care delivered;
- provide standards of provision in relation to quality/ comprehensiveness of the service; and
- plan more carefully the complementary roles of statutory and non-statutory services.

3.10 Research has clearly demonstrated that voluntary and community organisations (VCO) are cost effective, flexible, innovative, and pioneering (Wolfenden Committee, 1978). Knapp (1990) described the distinctive features of voluntary and community organisation. These included:

- provision of different specialised services;
- cost effectiveness of provision;
- flexibility and innovation; and
- advocacy and citizen participation.

3.11 An understanding of VCOs at commissioning and government level is necessary since many of the problems faced by VCOs are the consequence of a lack of understanding. The aim should be to maximise the distinctive contribution the VCOs bring to service delivery. The relationship between VCOs and statutory services needs to map the extent and variety of means by which the voluntary sector is already involved and to examine best practice in full partnership, (HM Treasury, 2002).

Funding Arrangements in the Voluntary and Community Sector

3.12 Current funding arrangements for the voluntary and community sector in Northern Ireland are problematic. Many projects are funded on a short-term basis. Many projects are only partly funded. Funding arrangements between government and the voluntary sector has been discussed in Guidance to Funders (2003) in an attempt to improve funding relationships for voluntary and community organisations. Two areas are of particular concern; stability in the funding relationship and the lack of long term funding arrangements; a continuing problem for VCOs. Recommendations for improving the situation are to involve VCOs actively in planning as well as service delivery and to ensure the price for a contract reflects the full cost. A new investment fund referred to in Guidance to Funders (2003) are the "Futurebuilders" fund which if implemented should be of assistance to VCOs in their work. High quality schemes that exemplify good practice, encourage partnership working and replicate success should be the main candidates for funding.

3.13 Currently in Northern Ireland a small number of services have been commissioned by the statutory services and this funding is outlined in statutory addiction service reports. These show an interface with 58 voluntary groups and an investment of 14% from the overall budget with such groups. There is however no overall audit of output or the nature/type of the agency contracted. Only details of those who contacted the service are presently noted.

3.14 Historical development of services has led to uneven growth and different philosophies of care. The absence of an agreed model of service delivery and variations of the scale and pattern mean that different services have evolved with different combinations of services. Some VCO agencies focus on outreach services, others on information and advice whereas others' main contribution is structured intervention treatment programmes.

3.15 VCOs funded to deliver a counselling service should be able to demonstrate their practice of counselling and be aware of paying particular attention to the areas which are known to provide better outcome. They should be asked to demonstrate their counsellors' supervision arrangements. Enough research has been carried out to inform us on best practice leading to better outcome. Trained, qualified and supervised staff are crucial in service delivery at VCO level. Furthermore UKATT (2004) suggests manual based treatment programmes can maximise outcome.

SUMMARY

3.16 The voluntary and community sector has a large part to play in the delivery of substance misuse services. It should be recognised that the VCO services have unique qualities for attracting and retaining certain client groups. Planning of services should bring together representatives from the voluntary and statutory services in equal partnership.

3.17 Funding arrangements for VCO should take note of the recommendation guidelines of government.

Recommendations

12. The range of community based voluntary services in Northern Ireland should be extended. This should be informed by local need, best practice and existing evidence of effectiveness. Consolidation of existing work and securing of long term funding should be a priority.

13. VCOs should be involved in planning of commissioned services.

14. Funding arrangements should be carefully planned in consultation with potential providers.

15. Clear commissioning guidelines should be given to services regarding the type of service required, specifications should be clearly defined. Clear protocols for referral and assessment procedures should be encouraged.

16. Monitoring guidelines for measuring activity and performance, waiting times, referrals, case management and partnership activity should be outlined and be uniform across Northern Ireland. These quality standards should be similar to those in statutory services.

17. Training minimum standards should be agreed by those who deliver commissioned services. Outline of standards should indicate recognised accredited courses only.

CHAPTER 4

COMMUNITY AND PRIMARY CARE SETTINGS

INTRODUCTION

4.1 Most treatment delivered to Drug and Alcohol Users is delivered within the community and primary care setting. This is also the setting for which there is the strongest evidence base for various counselling interventions. The evidence pertaining to the use of brief interventions is very strong (www.rmhldni.gov.uk) and this has informed our recommendation that the brief interventions should be readily accessible to every person in the population of Northern Ireland. There is an increasing evidence base supporting the use of motivational counselling. This counselling is very appropriately delivered at community and primary care level and forms the basis of much of the opportunistic counselling which can be delivered in various settings across our community.

4.2 The community domain allows integration of the statutory and non-statutory services. Good liaison and good strategic planning should address local need and should lead to these various sectors being enabled to produce maximum benefit to the population. The secondary addiction services have a strong role to play in education, liaison, consultation, support and enabling the other services to function appropriately in delivering the brief interventions and motivational interviewing for addiction problems.

4.3 We have recommended the adoption of the tiered approach to addiction care as outlined in the Models of Care described by the National Treatment Agency for Substance Misuse (www.nta.nhs.uk). Tiers 1, 2 and 3 of this model are delivered at community and primary care level. These are described in detail in the following sections.

Tier 1 Services

4.4 Non substance misuse specific services requiring interface with drug and alcohol services.

4.5 Specialist staff should support primary care staff in the delivery of interventions. Community Addiction Team staff should be involved. Link workers should be considered in areas with high need, for example, to homeless services.

4.6 All drug and alcohol misusers in Northern Ireland should have local access to:

- the full range of health and social care, housing, vocational and other services;
- drug and alcohol screening assessment and referral mechanisms to services from generic health and social care and criminal justice settings;
- the management of drug and alcohol issues in generic health, social care and criminal justice settings;
- health promotion and advice; and
- hepatitis B vaccination programmes.

Tier 2 services

4.7 Open access drug and alcohol treatment services. These are accessible drug and alcohol specialist services, provided by the statutory and non-statutory services. There is a low threshold to access these services. There should be ready access to referrals from a variety of sources, including self-referral. The families and carers for people with drug and alcohol problems should also be able to access low threshold, easy access services for support and counselling.

4.8 In Tier 2 there are limited requirements on users to receive services. Often, Tier 2 services provide access to Tiers 3 and 4. The aims of Tier 2 services include engagement of the client into the treatment structures.

4.9 Tier 2 must be staffed by competent specialist substance misuse staff. This staff group has strong training needs. This work is as highly specialised (and sometimes more so) as that of Tiers 3 and 4.

4.10 Drug and alcohol misusers in Northern Ireland should have access to the following services:

- motivational and brief interventions for drug and alcohol users;
- drug and alcohol related advice, information and referral services for misusers (and their families), including easy access or drop in services;
- services to reduce the risks caused by injecting drug misuse, including needle exchange facilities (in drug treatment services and pharmacy based schemes);
- services that minimise the spread of blood borne diseases to drug misusers, including service based and outreach facilities;

- services that minimise the risk of overdose and other drug related harm;
- outreach services targeting high risk and priority groups; specialist drug and alcohol screening and assessment, care planning and management; and
- criminal justice screening, assessment and referral services; and prescribing, supply and administration services which aim to promote medicines management and governance in the use of medicines.

4.11 Some marginalised groups within our society, including children and those with learning disability may have greater difficulty in accessing these services than the rest of the population. Separate chapters are devoted to the work of delivering drug and alcohol services to young people and to design and delivery of services to people with learning disability. It must be emphasised that all of these services must be available and easily accessible to our entire population.

Tier 3 Services

4.12 These are structured community based drug and alcohol treatment services. These include:

- psychotherapeutic interventions, e.g. cognitive behaviour therapy;
- motivational interviewing interventions;
- structured counselling;
- methadone maintenance programmes;
- community detoxification;
- day care in drug and alcohol free programmes;
- day care as an adjunct to methadone treatment; and
- aftercare following residential treatment for drug and alcohol problems.

4.13 A comprehensive service requires all of these, tailored to individual need.

4.14 Tier 3 services require a higher level of responsibility on the part of the client. These services require the user to undertake:

- a full assessment;
- a care plan agreed by service provider and client; and
- a structured programme of care. This may involve requirements on behaviour and attendance.

4.15 A care co-ordinator may be appropriate for complicated cases. In some services a senior member of the Community Addiction Team may be commissioned to carry out this function. In other services, commissioners may wish to separately appoint care co-ordinators. This area needs attention.

4.16 There may be variation in the level of provision of Tier 3 services depending on geographical factors. For example, day care may be more appropriate in urban than rural areas. Because of the nature of the specialisation and economies of scale it may not be possible to provide all services in all localities. The issue of access to services is the key and we aspire to access to all services for all people living in Northern Ireland.

4.17 Specialists in a Tier 3 service may need to work closely with other specialist services to meet the needs of specific client groups. For example, close working with the mental health services is necessary in order to ensure a good service for clients with dual diagnosis.

4.18 All problem drug and alcohol users in Northern Ireland should have access to a range of therapeutic interventions provided by skilled and knowledgeable service personnel. Based on individual need, these might include the following:

- support to access and utilise appropriate self-help services (Annexe 4);
- community based detoxification services;
- a range of specialist stabilisation and maintenance prescribing services;
- shared care prescribing and support treatment through primary care;
- a range of structured care plans, counselling and therapies;
- therapies for drug and alcohol problems, available through the criminal justice system;
- structured day programmes;
- services targeting specific groups of clients, e.g. adolescent drug and alcohol services;
- liaison services for drugs and alcohol for acute, medical and psychiatric services;
- aftercare programmes or support; and
- families of those with alcohol and substance use problems should be offered support and the opportunity to be involved with therapy, where appropriate.

4.19 Particular attention must focus on groups of people who may be marginalised within society. This applies to some ethnic minority groups and to people with mild learning disability. The commissioning process must ensure that the needs of all population groups are met.

Recommendations should be read in conjunction with Annexe 4.

Recommendations

18. The tiered approach, recommended by Models of Care, should be adopted in the delivery of treatment for drug and alcohol problems.

19. Commissioning structures must be developed, with clear lines of accountability, to ensure comprehensive development of all tiers of delivery in all geographic areas.

20. Service providers should describe their services in keeping with the tier system.

21. All problem drug and alcohol users in Northern Ireland should have access to a range of therapeutic interventions provided by skilled and knowledgeable service personnel.

22. Benchmarks should be developed for all skill levels for Northern Ireland to allow commissioners to allocate staff resources effectively.

CHAPTER 5

RESIDENTIAL PROVISION AND REHABILITATION

INPATIENT HOSPITAL TREATMENT

Philosophy

5.1 Some people with substance use dependence have difficultly achieving abstinence in the community. Inpatient programmes are therefore designed for those drug and alcohol misusers whose needs require supervision in a controlled medical environment. Such services provide a valuable safety-net in the management of complex cases within the community.

5.2 Inpatient drug and alcohol misuse treatment is a Tier 4 service. In order for inpatient services to function appropriately and effectively Tiers 1 – 3 must be properly staffed with trained staff at adequate manpower levels. Inpatient drug and alcohol misuse treatment programmes are specialised units for people with drug and alcohol misuse disorders. They provide medically supervised assessment, stabilisation and withdrawal with 24-hour medical cover and a multi-disciplinary team. Programmes also include a range of additional provisions such as Relapse Prevention work and aftercare referral services.

5.3 Inpatient treatment can facilitate the provision of the following specific prescribing interventions:

- stabilisation on substitution opioids (e.g. methadone);
- withdrawal from substitution opioids (e.g. methadone);
- withdrawal from opioids using non-opioid medication (e.g. Lofexidine);
- stabilisation on benzodiazepines for sedative (including alcohol) withdrawal;
- withdrawal from benzodiazepines for sedative (including alcohol) withdrawal;
- opioid relapse prevention with Naltrexone; and
- symptomatic treatment for stimulant withdrawal.

5.4 It might also facilitate psychotherapeutic interventions e.g. Social Behavioural Network Therapy.

Location

5.5 In the United Kingdom such inpatient beds are provided in specialist units, general hospitals and general psychiatric hospitals. The evidence base favours dedicated inpatient units which achieve better outcomes. In Northern Ireland, all 5 hospital units are currently specialist units.

Programme Duration

5.6 The usual length of stay on a withdrawal programme is between 2 and 7 weeks with an average of 4 weeks (Taskforce to Review Services for Drug Misusers, 1996). In the National Treatment Outcomes Research Study (NTORS) the duration of inpatient treatment varied from 2 – 5 weeks. Research suggests that longer periods in treatment may predict better outcomes (Gossop et al, 1999). There is an indication of a "critical period" of 28 days for opioid users in this respect.

Staffing

5.7 Inpatient units are usually staffed by multi-disciplinary teams (Taskforce to Review Services for Drug Misusers, 1996). In Northern Ireland we aspire to recognise the holistic spectrum of interventions e.g. family and carer interventions, psychological treatments, occupational interventions (Copello, 2002).

Aims and Objectives

5.8 The appropriate aims and objectives are outlined in the Models of Care of the National Treatment Agency for Substance Misuse. These are listed as follows:

- to fully assess the psychological, psychiatric, social and physical status of patients using clearly defined assessment schedules;
- to fully assess the degree of dependence on various classes of drugs, including assessment instruments as indicated, e.g. opioid and benzodiazepine dependence schedules (Ghodse, 1995) or alcohol dependence assessment instruments (Stockwell et al, 1979);
- to define an individual care plan for every client and to ensure that a named key worker has responsibility for the planned package of care;
- to carry out a risk assessment;
- to prescribe medication where indicated, according to clearly defined protocols and as part of a comprehensive programme of care;
- to prescribe medication safely and effectively in order to achieve stabilisation and/or withdrawal from psychoactive substances;

- to prescribe medication appropriately for relapse prevention;
- to prescribe medication for psychiatric and/or physical complications and/or co-morbidity as appropriate;
- to identify risk behaviour and offer appropriate counselling to enable minimisation of harm;
- to offer appropriate tests for hepatitis B and C and HIV with informed consent;
- to provide hepatitis B prophylaxis where indicated;
- to assess the longer term treatment needs of patients and formulate an appropriate discharge care plan in accordance with a care programme approach;
- to provide a period of drug-free recovery as appropriate;
- to provide effective psychological interventions, such as cognitive behavioural therapy and relapse prevention therapy;
- to assess and refer patients for other treatments as appropriate, e.g. trauma therapy, family therapy etc;
- to monitor and evaluate the efficiency and effectiveness of prescribing interventions;
- to monitor and evaluate the efficiency and effectiveness of psychological interventions; and
- to provide referral to other services as necessary, including medical services (e.g. hepatology, communicable diseases etc), psychiatric services, social and community services (e.g. housing, legal advice centres, children and family social services).

Eligibility

5.9 Admission to inpatient Drug and Alcohol Misuse Treatment Programmes is voluntary. Most units are adult units. The target groups for inpatient treatment are:

- patients physically dependent on 1 or more classes of drugs;
- patients with physical or psychiatric complications or co-morbidity;
- patients with chaotic polydrug use;
- women who are pregnant;
- patients who have failed to complete outpatient drug treatment programmes; and
- patients who are unlikely to cope with outpatient detoxification due to significant personal isolation or lack of support from family or friends.

Priority Groups

5.10 People with the following characteristics are priority groups:

- severe dependence;
- co-morbidity;
- pregnancy, puerperal problems;
- withdrawal complications;
- significant personal isolation; and
- people with chaotic, unstructured lifestyles.

Exclusions or Contraindications

5.11 These include:

- serious acute psychiatric morbidity, e.g. acute psychosis, requiring acute psychiatric treatment;
- serious physical morbidity (e.g. life threatening physical illness); and
- admissions may be carefully timed e.g. in the case of a couple both requiring inpatient treatment, to avoid compromising individual care.

Access

5.12 Access to inpatient treatment should be through the Tier 2 and 3 services. Access should only follow full assessment co-ordinated by the care manager.

Referral Pathways

5.13 Services should develop clear care pathways including referral pathways and assessment protocols.

5.14 Services should develop clear written policies on discharge for reasons of safety, transfer of patients to other hospitals and discharge plans.

5.15 Clients may be asked to agree to a contract of care which specifies that certain behaviours are not acceptable. In the United Kingdom such contracts commonly include the use of illicit drugs during inpatient treatment, racist or sexist behaviour and violent behaviour. Where such contracts are in place, patients are asked to agree this contract as a condition of accepting treatment in the unit, with the understanding that a breach of this contract will lead to a review of treatment and possibly to discharge.

Residential Rehabilitation

5.16 Residential rehabilitation for dependent drug users provides structured treatment programmes delivered in residential, or hospital inpatient environments. Admissions may be short-term (6-8 weeks) or long-term (12-52 weeks). In some cases, clients may move from a rehabilitation programme to a half way house.

5.17 Most residential rehabilitation units are run by non-statutory services who may have a range of treatment philosophies and operational policies.

Recommendations

23. Inpatient units should continue to be maintained separately from general psychiatric beds in Northern Ireland.

24. Inpatient beds should be commissioned to meet current and future demands locally. Bed numbers should match Royal College of Psychiatrists recommendations of 3 beds per 100,000 general population.

25. The planned length of opiate detoxification programmes should be at least 4 weeks.

26. Adequate staff levels should be maintained. Nurse staffing levels should be enhanced to meet Telford Recommendations. Staffing should be provided by multi-disciplinary teams.

27. Services should develop clear care pathways including referral pathways and assessment protocols. There should be clear written policies on discharge for reasons of safety, transfer of patients to other hospitals and treatment plans. Aftercare procedures must be in place. Development of these policies should involve service users.

28. The role of Community Addiction Teams in screening potential admissions should be strengthened to ensure "seamlessness" of services. Local conditions may influence this development.

29. Access to inpatient beds should only follow full assessment of the patient. This should be co-ordinated through a care manager.

30. Where Contracts of Care are in place, agreement of the patient must be sought in advance of the arranged admission.

31. The holistic spectrum of interventions should be recognised, with employment of family interventions.

32. An audit of local residential rehabilitation options should be undertaken in Northern Ireland.

33. Information on existing residential rehabilitation treatment options should be collated and made more widely available.

CHAPTER 6

INTERFACE WITH GENERAL HOSPITALS

INTRODUCTION

6.1 The Royal College of Physicians (London) have reported that alcohol “plays a direct or contributory role in between 7-40% of all acute, non-A&E, hospital admissions”, and has recommended that all hospitals should have an alcohol strategy. Individuals who are drinking at hazardous or harmful levels may present with a wide variety of medical or surgical disorders, trauma, or deliberate self-harm. On occasions it is the victims of people who have been drinking alcohol who require medical attention. The overall inpatient costs of alcohol misuse may be between 2-12 % of total NHS expenditure on hospital services.

6.2 One study carried out in a Belfast hospital found that 16% of medical in-patients and 39% of A&E patients were drinking at hazardous or harmful levels.

6.3 A joint Royal College of Physicians (London) and Royal College of Psychiatrists Working Group has called for specialist liaison services to manage patients with alcohol and drug problems.

6.4 Patients on admission to general hospitals or indeed psychiatric hospitals should routinely be asked by medical and nursing staff about their use of alcohol. Detection of alcohol misuse can be improved by better history taking, maintaining a high index of suspicion for alcohol related disorders, measuring possible laboratory markers of alcohol misuse such as mean corpuscular volume and liver function tests, and the use of brief alcohol screening questionnaires. These include CAGE, AUDIT (Alcohol Use Disorder Identification Test) and FAST (Fast Alcohol Screening Test).

6.5 The general hospital provides the ideal setting for opportunistic interventions. The provision of specialist staff would enable a range of such interventions, including the brief interventions and early interventions. Some dependent drinkers will require more intensive treatments.

6.6 Delirium tremens is a potentially life threatening condition which develops during withdrawal from alcohol in some severely dependent individuals and requires treatment in a general medical hospital. It is characterised by symptoms including visual and/or auditory hallucinations, paranoid delusions and autonomic over-activity. Patients with delirium tremens can present major management problems in a medical setting. The full-blown syndrome can often be averted if appropriate treatment is instigated in a timely fashion. It can be helpful to monitor the progress of the patient using an alcohol withdrawal scale, such as the CIW A-Ar. Any co-existing serious medical condition such as a subdural haematoma, head injury, infection, electrolyte or metabolic disorders need to be promptly identified.

6.7 Wernicke's encephalopathy is caused by acute thiamine deficiency and should be suspected in any patient with a history of alcohol misuse and any of the following symptoms or signs:

- confusion;
- ataxia, especially truncal ataxia;
- opthalmoplegia;
- nystagmus;
- memory disturbance;
- hypothermia and hypotension; and
- coma.

6.8 Treatment should be with Parenteral Thiamine, in a general hospital setting. Failure to detect and adequately treat Wernicke-Korsakoff syndrome may lead to long-term disability with persisting impairment in new learning and inability to maintain independent living.

Recommendations

34. Each general hospital should have a policy on the management of alcohol intoxication and alcohol withdrawal, and associated medical conditions such as Wernicke's encephalopathy.

35. Staff working in the general hospital setting should be offered training and support to opportunistically deliver brief interventions to reduce the harm associated with alcohol misuse.

36. Specialist alcohol liaison services should be developed to provide prompt advice and treatment for individuals in general hospitals with alcohol dependence who are unlikely to respond to brief interventions. Referral pathways to liaison services should be clear.

CHAPTER 7

HARM REDUCTION SERVICES FOR INJECTING DRUG USERS

BACKGROUND

7.1 Harm reduction is a widely used term in public health related literature and is assuming high importance within the drug prevention and treatment fields. This is due to the rise in incidence of injecting drug use and related spread of blood borne viruses. Through the Drug and Alcohol Strategies (DHSSPS, 2001), emphasis is being placed on drug workers adopting harm reducing approaches to care as well as promoting positive health education messages for injecting drug users.

7.2 The idea of reducing harm associated with drug use is firmly vested in public health practice with "secondary prevention" to "high risk" groups. It is not a new approach so much as it is an extension of and a focusing on existing and accepted approaches. Harm reduction fits well within the conceptual framework of health promotion, with the minimisation of risks and harm; forming one part of the continuum of strategies to promote health and avoid disease (CCSA, 1996). Both approaches emphasise the importance of respecting individuals and empowering them to increase opportunities to maximise their health, whatever the circumstances. From a community perspective, containment of drug related harms might be a more pragmatic option than efforts to eliminate drug use entirely.

7.3 In Northern Ireland, embracing harm reduction approaches for the injecting drug using population presents new challenges for those working in this field that aim to reduce the negative consequences of drug use. Risks include:

- blood borne viruses, hepatitis B, hepatitis C and the spread of HIV;
- direct damage to the injection sites and potential bacterial infections;
- general neglect of personal health and overdose;
- increasing levels of drug dependency;
- family and relationship breakdown;
- acquisitional crime leading to criminalisation; and
- homelessness.

CURRENT SERVICE PROVISION IN NORTHERN IRELAND

Outpatient Counselling and Support (Substance Related)

7.4 Community Addiction Teams offer case management approaches, from harm reduction to abstinence-based models, which are dependant on the client's goal of choice. A Motivational Interviewing approach underpins the assessment and counselling interviews. This approach provides a theoretical framework that is consistent with the values underpinning harm reduction work.

Detoxification

7.5 Detoxification means the assisted withdrawal from dependent drug use – mainly opiates such as heroin. A prerequisite for "detox" is the need for general practitioner involvement.

Inpatient Insight-Oriented Group Work

7.6 The prevailing eclectic model based on Minnesota principles includes a commitment to the goal of total abstinence. Clients express an interest in this type of intervention and engage in an assessment process lasting several weeks. Stability and abstinence are prerequisites.

Relapse Prevention

7.7 This is a Cognitive Behavioural model, aimed at clients who have achieved a period of stability.

Outreach Services

7.8 Currently 2 outreach services exist in Northern Ireland. The establishment of such services addresses the issue of identifying and building relationships with those people who have not engaged with established addiction services. Marlett et al (1996) point to evidence demonstrating that disaffected injecting drug users approach and engage with low threshold outreach projects with more frequency than with established addiction treatment centres. This provides opportunities to convey health promoting and risk reduction messages. In other areas in the United Kingdom this service extends to needle exchange known as "back packing", which is carried out by outreach team members.

Limited Needle Exchange

7.9 The exchange of needles was agreed locally with longstanding injecting clients well known to services. This was superseded by 9 pharmacy based needle exchanges throughout Northern Ireland.

Substitute Prescribing

7.10 Substitute prescribing of opiate drugs commenced as policy in Northern Ireland on 1 April 2004. This involves the prescription of substitute opiates, usually methadone or Subutex, to those who are dependent on opiates. The primary goal is to reduce the incidence of injecting drug misuse by dispensing the substitute drugs in a form which is designed for oral use.

7.11 In Northern Ireland, initial prescription of substitute drugs is by the secondary services, moving to a shared care model where general practitioners prescribe for stable, established substitute users. Supervised daily consumption in community pharmacy is the norm for at least the first 6 months of treatment. A key worker is provided by the secondary service. A harm minimisation approach is adopted and excessive alcohol or benzodiazepines ingestion is discouraged.

7.12 Opportunistic viral testing, education and hepatitis B vaccination are employed. Motivational counselling, supportive counselling and relapse prevention are also offered.

CONCLUSIONS

7.13 In order for harm reduction messages to be conveyed successfully drug treatment workers must look at ways of engaging people in treatment, addressing the issue of what influences them in seeking help and continuing engagement with drug treatment services. They should also seek to raise the publics' awareness of these issues. This is essential if community issues such as blood borne viruses and drug-related crime are to be addressed and the needs of the injecting drug population are to be met.

7.14 Annexe 7 offers the interested reader a summary of the historical context of harm reduction strategies and of their effectiveness. The research literature indicates that best practice should offer clinical direction and leadership in promoting a wider range of options for service users, adopting harm reduction values and techniques in practice and equipping service providers with extensions to their knowledge and skills in harm reduction and the embracing of cultural change.

Recommendations should be read in conjunction with Annexe 7.

Recommendations

37. Educational materials based on harm reduction principles should be developed for appropriate target groups.

38. The experience of outreach programmes in Northern Ireland should be considered with a view to extending such schemes where appropriate.

39. Pharmacy needle exchange should be extended throughout Northern Ireland. There should be an exploration into the efficacy of outreach/community exchange as a key element of preventing the spread of blood borne viruses. These needle exchanges can act as a pathway to other helping services.

40. Training should be provided to ensure skilled and knowledgeable service providers. Training should include: safer injecting techniques, blood borne virus pre and post test counselling, clinical issues in blood borne virus transmission and epidemiology, person centred practice, substitute prescribing and opiate detoxification.

41. There should be an emphasis on person centred holistic care and service user involvement in treatment planning.

42. Treatment protocols and philosophies should be agreed throughout Northern Ireland to ensure equity of treatment for service users.

43. DHSSPS should review the operation of substitute prescribing in Northern Ireland by April 2007.

44. DHSSPS should respond in a timely fashion to resource implications of any escalation in the need for substitute prescribing.

45. GPs and community pharmacists involved in substitute prescribing should be offered appropriate education enabling them to initiate substitute prescribing in primary care.

46. Substitute prescribing programmes should be available in prisons as recommended in the Northern Ireland Guidelines on Substitution Treatment for Opiate Dependence.

47. Law enforcement agencies, community groups and drug users should work together to develop harm reduction policies and programmes that incorporate balanced responses to drug problems in the communities.

48. "Wet hostels" should be considered, providing drug users with high tolerance, low threshold accommodation in targeted areas.

CHAPTER 8

CHILDREN AND YOUNG PEOPLE

BACKGROUND

8.1 This chapter addresses substance misuse services for young people aged 17 and under. Very limited services exist for this target group and all existing services report under-resourcing.

8.2 Substance misuse has increased in Northern Ireland among 11-15 year olds throughout the 1990's. Population surveys addressing this age band show that 42% currently drink alcohol at least a few times each month and that 32% of boys who drink monthly report being drunk more than 10 times. Current drug use has increased from 5.6% in 1994 to 27.2% in 2003 in year 12 children. The interim findings of the Youth Development Study carried out by Queens University, Belfast showed that at least 12% of children aged 15 use drugs on a regular basis. This has major implications for the future which include the need for early directed interventions, the targeting of high risk groups and the exploration of harm reduction approaches (McCrystal et al, 2005).

8.3 **Vulnerable Young People.** Home Office research in the United Kingdom (1998) shows that higher levels of drug use exist in certain groups of young people who:

- have truanted or been excluded from school;
- have committed crimes;
- have been homeless;
- have run away from home; and
- are with a familial drug user.

8.4 In addition to these groups some research in Northern Ireland indicates that children experiencing trauma associated with the Troubles would be an additional group of concern (Kilkelly et al, 2004).

Prevention

8.5 In Northern Ireland there is emphasis on the prevention of alcohol and substance misuse in young people, with prevention programmes based in schools and the community. Substantial work has occurred across both the statutory and voluntary/community sectors. In many parts of the United Kingdom prevention and treatment strategies are provided together under a single strategy for young people. In those instances, local young people's substance misuse plans are developed through drug action teams in conjunction with children's services planning.

Treatment Services in Northern Ireland

8.6 Many services across health, education, criminal justice and the voluntary and community sectors will come into contact with young people requiring help and support as a result of their substance misuse. Until 2001, in Northern Ireland these services were supported by a small number of drug and alcohol services.

8.7 In 2001, a number of partnerships between voluntary sector services and the Community Addiction teams were established to provide a youth counselling service. This was in response to a growing recognition for the need to develop more accessible services for young people. Only one of these projects provides services exclusively for those aged under 18. A further project was developed targeting young substance misusers coming to the attention of the Police Service of Northern Ireland.

8.8 All of the services are recognised as Tier 1 and 2 services of the Health Advisory Service model, Annexe 8. Tier 3 or 4 drug and alcohol services have not been developed for children and young people.

8.9 Current Child and Adolescent Mental Health service provision is not adequately resourced to deal with those children and young people who have serious drug and alcohol problems.

Needs Assessment

8.10 In light of the perceived gaps in young people's treatment provision, the DHSSPS (2004) commissioned a needs assessment on youth treatment services across Northern Ireland.

8.11 A range of agencies across health, education and criminal justice responded to the exercise. Few agencies had policies or guidelines for working with those under 18 years who were using substances. Many respondents indicated that training in this area was a major gap. The commonest types of substance misuse in young people were alcohol, cannabis, solvents and ecstasy. The problems reported by young people in connection with their substance misuse included school absenteeism, parental conflict, criminal activity, sexual risk taking, violent behaviour and debt problems.

Interventions for Adolescents with Substance Use Problems

8.12 Many treatments for young people have been adapted from Adult Addiction and Child and Adolescent Mental Health fields. These include cognitive and behavioural therapy, motivational interviewing, relapse prevention, family and multi-systemic family therapy. There is also a role for information and brief interventions in this age group.

8.13 The Review of Literature carried out by DHSSPS (2004) notes that interventions for children must be developmentally appropriate. Adult models of alcohol and drug misuse, including diagnostic typologies and classification systems, may not accurately reflect the development and course of problem substance use in young people. It cannot be assumed that interventions that work with adults will also work with young people. In addition, interventions for adolescents must take into account gender, ethnicity, disability, stage of readiness to change as well as cultural background and other treatment relevant characteristics. The provision of drug misuse interventions to young people is governed by a different legislative framework, than that for adult services in particular the Children's Order (1995). Programmes should make every effort to involve the adolescent client's family. Accessibility of services is a key concern. Efforts should be made to remove potential barriers to accessing services.

8.14 Medications may play an important part in delivery of drug services for some young people, particularly those with serious drug problems. This should be combined with counselling and other behavioural therapies.

8.15 Consultation exercises with young people carried out before and during this review reaffirm the need for:

- child and young people specific services;
- services which provide much more than treatment, e.g. lifeskills, music, sport and diversionary activities;
- education for parents;
- family involvement in treatment and support services; and
- attention necessary with respect to the structuring of services for young adults aged 18 – 25 years.

SUMMARY

8.16 There is an urgent need for the development of an integrated framework of care for children and young people in all areas incorporating all of their needs in relation to alcohol and other substance use. Inadequate provision of essential treatment and support services to children and young people represents a failure to actively protect and promote their rights.

8.17 There is a clear need for a pro-active innovative approach to the development of future services for children and adolescents with substance misuse. This should include strategic direction and adequate resources for both training and provision of services.

Recommendations

49. A co-ordinated, multi-agency, long-term specific strategy for substance misuse services should be developed for young people under 18 years of age. This strategy should involve, in particular, the education, training, health, criminal justice and child care sectors. This must be underpinned by recurrent funding and supported by appropriate implementation structures. This would build on the existing alcohol and drug strategy and should be integrated within existing children's services planning.

50. The four-tier approach recommended by the Health Advisory Service (1996) should be applied at a local and regional level to include education, assessment, prevention and treatment and should be based on the Models of Care principles. Priority needs to be given to Tiers 1, 2 and 3 with emphasis placed on community based services (see Annexe 8).

51. Services for children/young people, including vulnerable groups, should be underpinned by standardised screening, assessment and treatment protocols and tools. These should reflect the holistic nature of the child's/young person's needs and not focus only on the child's/young person's substance misuse.

52. All services for children and young people must attempt to deal with the needs of young people within their natural environment and background. This should involve work with the family.

53. Those working with under-18s should demonstrate a multi-disciplinary, inter-agency approach and staff/personnel must be suitably trained to meet the requirements of their role and responsibilities (see Annexe 8).

54. Standard information gathering processes should be designed and disseminated in order to support the future needs assessment of children's/young people's treatment services.

55. Future research should examine the impact of regular substance use on the vulnerable groups of children and young people as listed in 8.3.

56. Existing provision for children and young people should be sustained and developed. A review to ensure these services are specific to this age group i.e. under 18s is required. Funding should be earmarked for development of services specifically for those under 18.

57. Commissioning bodies should be given the appropriate resources to implement children's/young people's services plans and strategies. Adult services should also be encouraged to address the particular needs of young adults aged 18 – 25 years. These plans/strategies must include the participation of young people through reference groups such as the model currently being piloted by the WHSSB Children's Services Plan.

58. Specific substance misuse services for children and young people should be developed in each health board area based on partnership models across all sectors.

CHAPTER 9

PEOPLE WITH LEARNING DISABILITIES

INTRODUCTION

9.1 This section examines substance misuse in people with learning disabilities. We discuss the issues relating to the definition, prevalence rates, the risk factors that may cause and maintain substance misuse, and examine the impact that such misuse has for the person (see Annexe 9). We review the identification, assessment, treatment, management strategies and services that are currently employed for this population in light of best practice using a bio-psycho-social framework (see Annexe 9). Alongside this synopsis of the literature on this subject matter, the Review of Mental Health & Learning Disability (Northern Ireland) commissioned a study on substance misuse in people with learning disabilities living in Northern Ireland. Details of this innovative and comprehensive study are available at: www.rmhldni.gov.uk

9.2 This section provides a series of recommendations that are established upon this study and supplemented with the most recent empirical evidence from across both sides of the Atlantic (IASSID, 2001, Stavrakaki, 2002, Sturmey et al., 2003).

Definition

9.3 The term “learning disability”, as used throughout this report is that favoured by the Review. The definition is discussed in the Equal Lives report (para 3.11. etc). People with learning disabilities who also have a mental health problem have been labelled with the term “dual diagnosis”, however this term has been traditionally associated with a psychiatric disorder and a substance disorder. Barnhill (2000) further coined the label “triple diagnosis” for people with learning disabilities who have a mental health problem and a substance related problem.

Learning Disabilities and Substance Misuse

9.4 There is a large body of empirical evidence to emphasize that people with learning disabilities have been segregated and marginalized from society regarding housing, employment, education and also health. However, recent changes in legislation across both sides of the Atlantic have strongly advocated the social inclusion, citizenship and empowerment, wherever possible, for this population in all areas of society (DHSS, 1996, Dept. of

Health, 2001, Same as You, 2001): and the Equal Lives Report: www.rmhldi.gov.uk

9.5 As more people with learning disabilities are living in accommodation in the community with minimal support, they may be exposed to greater social stressors leading to increased use of alcohol and drugs as a coping mechanism or stress reliever (Longo, 1997, Mc Gillicuddy & Blane, 1999, Barnhill, 2000, Sturmey et al., 2003). The person with a learning disability may then see alcohol and drugs as a method of "fitting in" and "socialising" with his or her peer group. This process of "fitting in" may compensate for the isolation, poor social skills, inadequate supports, friendships, relationships and consequent frustrations frequently described by people with learning disabilities. (Moore & Polsgrove, 1991, Gress & Boss, 1996, Clarke & Wilson, 1999, Sturmey et al., 2003).

Service Provision for this Learning Disability Population

9.6 The needs of people with learning disabilities who misuse substances have rarely been addressed. Some mainstream addiction services exclude this population highlighting a lack of knowledge (Lottman, 1993, Degenhardt, 2000). Some learning disability service providers struggle to manage this doubly challenged population claming a lack of knowledge regarding addictions. Consequently, many individuals continue to "fall through the cracks" across both service providers as they lack the appropriate personnel and resources to manage this population and that of their carers (Lance & Longo, 1997).

9.7 Campbell et al. (1994) identified 5 barriers to the treatment for chemical dependency among this population, these include:

- existing mainstream treatment models may need to be substantially adapted in view of their emphasis on insight, which may not always be attainable for people with learning disabilities;
- people with learning disabilities may lack the necessary skills to cope with and benefit from group-based therapies used for their non-disabled peers;
- the emphasis on effecting positive life changes may not reflect the real choices available to most people with a learning disability;

- dual diagnosis workers do not receive training in working with people with learning disabilities as part of their general training and may base their assessments and interventions on stereotypes or inaccuracies; and

- there is a low level of integration between services for people with a learning disability and mainstream addiction service making it difficult for professionals to work closely together.

9.8 The combined problems of substance misuse with learning disability, possibly with an additional mental health problem, greatly increases concerns regarding vulnerability and the capacity to make informed life choices. Mainstream addiction services often require an individual to have a high degree of motivation and a desire for change to benefit from treatment. People with learning disability need particular support to assist them to take part in such treatment when their capacity to make informed life choices is impaired.

9.9 The Addiction Resource Agency for Commissioners (ARAC) (2002) and the Borough of Wandsworth Study (2003) both reported that current learning disability service providers had no identified strategies regarding inter-agency working and joint care planning for this population. Referral to mainstream addiction teams by community learning disability teams was ad hoc with learning disability service providers often being given advice only. Annexe 9 and www.rmhldni.gov.uk discuss this situation in Northern Ireland.

9.10 A number of recommendations are provided in this section for future service provision in Northern Ireland.

Recommendations

59. People with learning disabilities and substance related issues should be able to access mainstream services. They are likely to require the support of learning disability personnel to utilise the services offered by the mainstream addiction teams.

60. There should be collaboration between learning disability and mainstream addiction services. This includes the development of a link expert based within learning disability services and also working in mainstream addiction services.

61. Screening tools should be explored to assist staff to detect possible substance-related behaviours, and also mental health problems.

62. A range of bio-psycho-social interventions should be available. These should be evidence-based, and embedded within the care plan which should be person-centred.

63. A health promotion schools strategy should be developed to target the health and well-being of people with learning disabilities.

64. A regional multi-professional interest group should be developed for planning, delivery, evaluation, promotion of current evidence-based practices and to promote further research for this population within Northern Ireland.

65. Particular efforts should be made to address people with learning disability living independently; with detection, support and education of those most at risk.

CHAPTER 10

OLDER PEOPLE

BACKGROUND

10.1 There has been increased research interest in the area of substance misuse among older people. In a review of current assessment, treatment and service provision 2 key reasons for this development were cited. The proportion of older people in the population is increasing and there are increased rates of alcohol users in the over 65 age group. Derry (2000) suggested that these 2 factors would "*present health and social services with a substantial challenge in providing interventions for this age group*".

10.2 In Northern Ireland, the percentage of people in the population over the age of 65 is projected to rise from 13% to 24% between 1996 and 2036 (Age Concern, 1999).

10.3 The prevalence of alcohol use is lower in the older population than it is for younger age groups. For example, 49% of 60 – 75 year olds drink, compared with 79% of 18 – 29 year olds. However among those older people who do drink, 31% of males and 18% of females exceed recommended safe drinking limits. This compares with 34% of males and 19% of females in the 30 – 44 year old cohort (Health Promotion Agency, 2002).

10.4 Older people may experience problems at relatively low levels of alcohol use due to physiological changes e.g. decreased lean body mass and lower body water content. Other factors including decreased hepatic blood flow, inefficiency of liver enzymes and neurological changes in the brain may result in a lowered tolerance to alcohol. It has been suggested that the recommended safe limits for older people be lowered to between ⅓ to ½ of those for the general population (Ward, 1998).

10.5 Older problem drinkers are usually classified using 2 categories; early onset refers to individuals who began drinking problematically before age 55 and late onset for those whose drinking became problematic after age 55. Early onset represents young problem drinkers who have survived into old age, while later onset is seen as a reactive form of alcohol misuse or a response to life stressors (Atkinson and Kofoed, 1982). These include retirement, bereavement, trauma, physical and mental health problems.

Incidence of Problem Drinking

10.6 Estimates for the number of problem drinkers range from 2 – 15% of the older population depending on factors such as age cohorts, population samples and definition of problem drinking used (Alcohol Concern, 2002).

10.7 There are several factors that have contributed to the lack of visibility of the issue e.g.:

- under reporting by older people, due to embarrassment or stigma;
- less contact with the criminal justice system; and
- less likely to encounter problems in the employment field (Atkinson and Kofoed, 1982).

Effects of Alcohol Misuse in the Older Age Group

10.8 Many of the physical, social and psychological problems experienced by older persons will also be a feature of problem drinking in other age cohorts. These may include:

- Hypothermia: Alcohol is a major implicated cause in patients admitted to hospital for hypothermia (Hislop et al, 1995);

- Delirium Tremens: The mortality rate for older persons with delirium tremens is higher than that for other age cohorts (Fuerlein and Reiser, 1986);

- Dementia: 10% of patients presenting with dementia have alcohol related brain disease (Dunne and Schipperheijn, 1989);

- Suicide: A history of alcohol dependence or misuse was noted in 35% of older male suicides and 18% of female suicides (Waern, 2003). Elderly people have a higher rate of completed suicide than any other age cohort (World Health Organisation in O'Connell et al, 2004);

- Depression: Incidence of depression ranges from 10% - 40% of the older population depending on definition used (Crome, 1991); and

- Elder abuse: Alcohol misuse is listed as a risk factor for both victim and perpetrator in the Illinois Risk Assessment Protocol (Baumhover and Beall, 1996).

Prescription Drugs

10.9 80% of people aged over 65 take prescribed medication on a regular basis. Polypharmacy is a common feature, with approximately ⅓ of those living in the community taking 4 or more prescribed medications at any one time (Alcohol Concern, 2002).

10.10 Pharmacokinetic differences in older people may result in higher blood levels for a given dosage regimen. Older people may be more likely to experience toxic effects and interactions of prescribed medications and alcohol (Morse, 1988). Problems with prescribed drugs may come from intentional or unintentional use eg contraindicated use or mistaken over or under use (Abrams and Alexopoulos, 1987).

Problem Identification

10.11 Problem identification necessitates an awareness of behavioural, cognitive and physiological indicators. Screening tools have been validated for use with this age group e.g. the Michigan Alcohol Screening Test (MAST). The MAST –G is a version specifically designed for older people and has been validated with reference to DSM-III-R criteria (Derry, 2000).

Treatment Services

10.12 Older people are not a homogeneous group; there is an age range of over 30 years. Factors contributing to the heterogeneity in this group include level of alcohol dependence, age of onset, co- morbidity and support networks. Individual treatment packages should be tailored to meet different client needs.

10.13 Close links between medical, social care and addiction treatment services are necessitated by the complex nature of biological, psychological and social factors involved. Multi-disciplinary inputs may be valuable in the assessment, treatment and post treatment phases. Family therapy may enhance the assessment process and provide ongoing support (Amodeo, 1990).

Recommendations

66. Addiction Services should be sensitive to the identified needs of older people with alcohol problems. Resources should be identified to meet the specific additional needs of the older population.

67. Commissioners should carry out a needs assessment on provision for older people with substance misuse in their catchment area. A regional initiative should be developed to form a perspective on provision of services for older people.

68. Treatment interventions for any service for older substance misusers should be evaluated.

69. Routine screening for alcohol abuse should be included in all initial assessments of older people admitted to hospital.

70. Awareness raising of alcohol related problems in the older age group, should be made available for hospital, primary care, social services and other health care staff. Training in the areas of identification, assessment and intervention strategies should be provided. Staff working in older people's services in both the statutory and voluntary sectors should be the primary focus for such training provision.

71. Multi-agency co-operation may be valuable in planning, assessment and individual treatment programmes for this client group.

CHAPTER 11

PEOPLE WITHIN THE CRIMINAL JUSTICE SYSTEM

INTRODUCTION

11.1 Offenders who misuse drugs or alcohol commit more offences than those who do not. There is a strong link between drug misuse and crimes such as shoplifting, burglary, vehicle crime and theft. Heroin, crack and cocaine misusers are responsible for 50% of these crimes and around 75% of crack and heroin users claim to be committing crime to feed their habits (Updated Drug Strategy, Home Office, 2002).

11.2 There is a complex relationship between offending and the prevalence of drug use:

- the use of drugs will have an effect on people's behaviour that will sometimes lead to them coming into conflict with the law;
- for some offenders their dependence means that their lives are disrupted to the extent that offending is more likely (for instance, the effect on employment, family stability, relationships etc);
- there are offenders for whom acquisitive crime is a means of financing their drug misuse and their level of offending would be reduced if they were not using drugs; and
- those involved in an offending lifestyle are more likely to be involved in drug use than those who do not otherwise offend. This is related to their greater impulsiveness, lack of social control and the norms of their peer group. This is supported by unpublished research on behalf of Probation Board for Northern Ireland (PBNI) into substance misuse among prisoners in HMP Maghaberry (2001). This found that 63% said they had used drugs in the past.

11.3 There are 4 main benefits to the community of providing treatment to offenders at an early stage:

- their offending rates drop, thereby protecting their potential victims;
- it focuses on a group who traditionally do not access treatment and thereby provides an opportunity to engage them in the system;
- treatment is likely to be more effective and efficient at an early stage before their drug problem becomes entrenched, therefore speeding their passage through the care system and freeing up services for others; and

- early treatment decreases the spread of blood borne diseases such as hepatitis and HIV (National Treatment Agency).

11.4 Assessment and treatment of alcohol and drug misusing offenders could occur in:

- police custody;
- court procedure;
- probation; and
- prison.

11.5 In England, through the Criminal Justice Intervention Programme, integrated care pathways for offenders have been established; however, treatment within prisons will still remain the responsibility of the Prison Service.

Police Custody

11.6 Individuals in police custody are entitled to the same standard of assessment and treatment as any other member of the public.

11.7 Urinalysis studies of people in police custody have demonstrated high levels of recent drug and alcohol consumption in over 60% (Bennett, 1998).

11.8 Police officers and forensic medical officers can provide information on local statutory and voluntary agencies offering assessment and treatment. This requires that all relevant Police Service of Northern Ireland staff have the requisite training to ensure that they are in a position to encourage individuals to take up treatment opportunities.

11.9 Arrest referral schemes are partnership initiatives set up to encourage drug misusers brought into contact with the police service to voluntarily participate in confidential help designed to address their drug-related problems (Edmunds, 1998). These can be of different models:

- Information model - the police give information regarding local services; and

- Proactive model - drug workers work in close co-operation with the police, often with direct access to prisoners, in providing an assessment either on site or at a subsequent meeting.

11.10 In Northern Ireland there are presently only 2 examples of arrest referral schemes. These are based in Ballymena and Londonderry. Without additional resources, people in police custody can only be advised on local services, missing an opportunity to engage a person into treatment.

Probation

11.11 The liability of young people to become involved in drug use cannot be separated from issues of family support, poverty, educational opportunities, employment and social cohesion. "While we welcome the measures taken to reduce supply, apprehend drug dealers and prosecute offenders appropriately, we advocate the support of individuals and communities as being equally important" (PBNI).

11.12 The PBNI is:

- an active participant in the implementation of the Drug and Alcohol Strategy for Northern Ireland, being represented on all relevant strategy groups;
- is represented on the 4 Drug and Alcohol Co-ordination teams by local area managers; and
- plays an active part in the management of specific projects in partnership with other statutory agencies and community groups.

Courts

11.13 At present, courts receive reports on offenders from both statutory and voluntary agencies.

11.14 Drug Testing and Treatment Orders have not yet been extended to this jurisdiction. If introduced in Northern Ireland this might provide some possible potential benefit for substance misusers and a more complete range of sentencing powers for the court.

Prisons

11.15 The Northern Ireland Prison Service (NIPS) has a primary duty to keep in custody those committed by the courts. It has 3 establishments:

- HMP Maghaberry – a high security prison housing male long-term and unconvicted prisoners, separated prisoners and male detainees at its facility close to Belfast;
- HMP Magilligan – a medium security prison housing shorter-term adult male prisoners, which also has low security accommodation for selected prisoners nearing the end of their sentence; and
- Hydebank Wood – a medium to low security establishment accommodating young offenders and all female prisoners.

11.16 It also has a responsibility to maintain and improve the health of prisoners, protect and promote the health of staff and strengthen links with families and the community.

11.17 WHO has set up a European network for promoting health in prisons. The aim of the network is to promote health in the broadest sense, within the prison community. It is built on a recognition that while imprisonment results in a loss of personal freedom, the negative effects of custody on health should be reduced to a minimum. It also endorses the principle that time spent in custody can be used positively to aid the prevention of disease, and as far as possible, to promote health (WHO, 2000).

11.18 Criminal justice integrated care pathways are described in Annexe 11. These would enhance co-ordination in Northern Ireland. Description of these pathways are to be found on the National Treatment Agency for Substance Misuse website (www.nta.nhs.uk).

Recommendations

72. People in prison should have access to the same service provision as the general population.

73. Arrest referral schemes should be evaluated and extended if shown to be beneficial in engaging clients previously difficult to engage.

74. Criminal justice integrated care pathways should be adopted (www.nta.nhs.uk).

75. Substance misuse teams, incorporating a harm reduction philosophy, should be appointed within each prison establishment.

76. On the grounds of public health, counselling and testing for HIV, hepatitis B and hepatitis C should be available for everyone.

77. Resources should be allocated for any new service.

CHAPTER 12

INTERFACE WITH MENTAL HEALTH SERVICES

INTRODUCTION

12.1 It is estimated that one third of individuals with a mental disorder have experienced a substance misuse disorder, one third of individuals with an alcohol problem have experienced a mental health disorder and one half of individuals with an illicit drug problem have experienced a mental health problem (Royal College of Psychiatrists, 2005).

12.2 The recommendations in the chapter on dual diagnosis contained in The Strategic Framework for Adult Mental Health Services www.rmhldni.gov.uk) have been reproduced in Annexe 12. They include a recommendation that people with a dual diagnosis of a severe and enduring mental disorder and substance use disorder are best treated by mainstream adult mental health services providing an integrated treatment service. These services combine high quality psychiatric care with substance misuse treatments such as motivational interviewing, cognitive behavioral therapy and family therapy over an extended period. However, even such high quality services have produced only modest reductions in substance misuse but they have demonstrated significant improvements in patient functioning when compared to routine care over 18 months (Haddock et al., 2003).

12.3 Marsden (2000) surveyed psychiatric symptoms among clients entering treatment for drug dependence and found that 29% of that group reported having suicidal thoughts in the previous 3 months, and 20% had received treatment for a psychiatric disorder other than drug or alcohol dependence in the previous 2 years.

12.4 A personality disorder may also co-exist with other mental disorders and substance use disorder. Welch (2003) reported that higher rates of antisocial personality disorder and borderline personality disorder are found in people with drug use disorders and to a lesser extent alcohol use disorders than in the general population. She noted that drug and alcohol users with personality disorders probably benefit from standard treatments for substance use disorders at least as much as those without personality disorder.

12.5 It may be difficult to determine with confidence whether substance misuse or a mental disorder is the primary problem at the time of the initial assessment. For example, abuse of stimulants may induce a psychotic state similar to that seen in acute schizophrenia but these symptoms usually settle following a brief period of abstinence in the absence of an underlying psychotic illness. Similarly, anxiety and depressive symptoms present in some individuals with an alcohol problem "may resolve following detoxification and standard treatment for alcohol dependence." SIGN (2003). These clinical presentations are frequently managed using a serial treatment model in which the initial treatment is provided by mental health services who will then refer the patient on to addiction services after the mental state has improved.

12.6 On occasions substance misuse services may need to combine with mental health services to work together in a parallel model of service delivery. Ideally mental health services should incorporate adequate numbers of staff who are trained to carry out substance misuse assessments and treatments within their own teams and who can also act as link workers with substance misuse services.

12.7 It is generally agreed that "community mental health teams have a responsibility to accept the management of people with a dual diagnosis where the severity of mental health disorder in a patient who misuses substances is significant or where there is diagnostic uncertainty" (Royal College of Psychiatrists, 2005).

12.8 Addiction services should be trained and resourced to meet the needs of those with a substance misuse disorder and who also suffer from less severe mental health problems, such as anxiety and mild depression.

12.9 Staff working in addiction services need to be skilled in the recognition of mental disorders given the high levels of dual diagnosis seen in addiction service. Assessment of suicide risk, and any potential risk posed to others, including children within the family, should be part of the routine assessment of alcohol or drug users presenting to treatment services.

12.10 Local guidelines are essential between mental health services and substances misuse services to clarify care pathways for individuals with co-existing drug or alcohol misuse, and mental disorder, including personality disorder.

12.11 Working with individuals with substance misuse problems and some types of personality disorder can be stressful for staff. Appropriate training and good support networks may help to protect staff from disillusionment or feelings of burnout.

12.12 High rates of psychiatric co-morbidity are found in the prison population, with only 1 prisoner in 10 reported as having no evidence of mental disorder (Reed, 2003). The strategic planning of criminal justice service initiatives linked with substance use services must take into account the likelihood of significant levels of psychiatric co-morbidity in this population.

Recommendations

78. Commissioners should make provision for people with mental health problems and co-existing alcohol or drug misuse. Local prevalence and needs of people with dual diagnosis should be assessed.

79. People with co-existing substance misuse and mental health problems should be treated using an integrated treatment model within a single service:

    - the needs of those with complex, enduring and relapsing mental disorders should be met by adult mental health services;
    - the needs of those with less severe mental health problems, whose main difficulties are directly related to substance misuse, can best be met by substance misuse services;
    - agreed arrangements need to be established between any specialist services for people with personality disorder and substance misuse services;
    - there should be systems of liaison between substance misuse and other mental health services to ensure that people with dual diagnosis have access to the full range of the most appropriate treatment services; and
    - physical health problems associated with substance misuse need to be identified and addressed.

80. The needs of people with co-existing substance misuse and mental health problems in contact with the criminal justice system should be identified and addressed.

81. There should be locally agreed clear care pathways between mental health and substance misuse services for dual diagnosis cases.

82. There may be benefits in having workers within mental health services with additional addiction expertise. They should have special responsibility for patients with a dual diagnosis, and make appropriate links with substance misuse services.

83. Staff working in adult mental health services and addictions services would benefit from joint training initiatives and a sharing of skills relevant to dual diagnosis. While mental health services may require training on the diagnosis and management of substance use disorders, staff working in addiction services require training and regular updates on the recognition of mental disorders, risk assessment, and the management of the less serious mental disorders.

CHAPTER 13

PREGNANT SUBSTANCE USERS

INTRODUCTION

13.1 The Confidential Inquiry Into Maternal Deaths (1997-1999) acknowledges that substance misuse in pregnancy causes major damage to the unborn child and the mother. It reported that there is increased risk of suicide and death in both drug and alcohol dependent women. It also found that substance misuse in women contributed to at least 25% of deaths due to psychiatric causes. The inquiry also highlighted that drug and alcohol dependent women could be characterised by their high levels of social adversity, homelessness, poor uptake of the services and poor attendance for either psychiatric or antenatal appointments. The inquiry recommended that open access to drug and alcohol services should be readily available and that this might improve engagement and compliance with care.

13.2 Women who drink during pregnancy face added risks. If the mother drinks between 7 and 14 units of alcohol per week, she doubles the risk of miscarriage. If she drinks more than 10 units a week in the first 3 months, her new-born child is more likely to have congenital deformity. Ten units a week may be associated with low birth weight (Royal College Physicians, 1995). Heavy drinking (i.e. more than 14 units per week), could result in the risk of giving birth to a baby with Foetal Alcohol Syndrome (FAS). Exact figures for UK are uncertain, however, it is estimated there are 200 affected babies born each year (Health Education Authority, 1994).

13.3 The Advisory Council on the Misuse of Drugs, which has a statutory duty to advise the Government on drugs of misuse and the health and social problems these may cause, completed a comprehensive report in this particular area. The report "Hidden Harm" (2003) highlighted 6 key messages from the inquiry:

- there are approximately 250,000 to 350,000 children of problem drug users in the UK – about one for every problem drug user;
- parental problem drug use can and does serious harm to children at every stage from conception to adulthood;
- reducing the harm to children from parental problem drug use should become a main objective of policy and practice;

- effective treatment of the parent can have major benefits for the child;
- working together, services can take many practical steps to protect and improve the health and well-being of the affected children; and
- the number of affected children is only likely to decrease when the number of problem users decreases.

13.4 The key areas of note included not only illicit substance misuse, but also the misuse of other readily available substances such as nicotine and alcohol (Johnston, 1998).

13.5 Miller and Dowds (2002) identified the increasing use of drugs and alcohol in young people in Northern Ireland. They reported that 6.8% of 12 to 16 year olds use drugs frequently and that 5.2% of 16 to 25 year olds used drugs and alcohol frequently. These are relevant facts considering that Northern Ireland has one of the highest incidences of teenage pregnancies in Europe. DHSSPS (2002) reports that the number of teenage births in Northern Ireland is 1,700 per year. With the increasing incidence of substance misuse in young people and the high incidence of teenage pregnancies it is vital that services are accessible to this vulnerable group. Plant (1997) also identified the highest proportion of women at risk were in the age group 18-24 years of age.

13.6 It is important to put substance misuse in the appropriate context. Even if substance misuse is an issue, most expectant mothers will have normal pregnancies with normal deliveries and minimal inconvenience caused to the family. However, there is a recognised need to support this group of women and ensure that all professions work together to provide support, help and advice which should minimise the risks associated with substance use.

13.7 Hidden Harm (2003) indicated that in England and Scotland 2-3% of children under the age of 16 live with problem drug users. In Scotland alone, this rises to 4-6%.

13.8 Hidden Harm (2003) also identified the variety of drugs that are misused by the expectant mother and impact of these on the foetus. Main drugs identified are:

- heroin and other opiates;
- cocaine and amphetamines;
- benzodiazepines;
- tobacco and cannabis; and
- alcohol.

13.9 Lothian NHS Board (2003) identified that the key areas of care should be focused on:

- pre-conceptual care – health promotion for all women of conceptual age;
- antenatal care – all expectant mums and significant others should be informed and supported regarding the risks of substance misuse during pregnancy – this early contact will allow a brief opportunistic intervention and screening process to commence;
- assessing risk during pregnancy – continuing risk assessment by health care professionals to ensure safety of all concerned. Cognisance should be taken of the fact that just because a women abuses substances she will not be fit to offer effective parenting;
- intrapartum care – care during labour will meet the specific needs of the mother; and
- postnatal care – postnatal care may require extensive support to help the family to adjust to needs of a baby and the needs of the person who misuses substance.

13.10 They recommended that substance misusers needed to be engaged in meaningful intervention and any approach to care should be tailored to meet the needs of this group of women.

13.11 Anne Whittaker (2003) suggested that the overall approach to care needs to be:

- women and family centred;
- non-judgemental;
- pragmatic, with an emphasis on harm reduction;
- holistic; and
- provided by a multi-disciplinary and multi-agency team.

13.12 A clear understanding of professional roles and responsibilities is paramount to maximise the quality of care. Collaborative working needs to promote the opportunity for care to be effectively co-ordinated where skills and knowledge can be jointly developed and the skills of each professional group utilised when needed. There are also a number of out-reach services to assist and support in the engagement of the expectant mother and the familyThese services have been identified as very effective means of bridging cultural gaps when caring for the substance misuser and their family (Shaikh and Reading, 1999).

13.13 Within Northern Ireland a number of agencies, both voluntary and statutory, are involved in meeting some of these needs of pregnant women with substance misuse. There are a number of educational agencies involved supporting staff working in this specific area of work.

13.14 Various agencies involved with education to nurses and midwives have taken a leading role in the provision of training to midwives. Other agencies including area child protection committees have provided multi-disciplinary training to primary and secondary care generic staff.

13.15 Whilst ensuring the appropriate services exist within Northern Ireland, it is equally essential to ensure that specialist training is provided to meet the needs of this group of women and their professional support services.

13.16 Within the social services context Guthrie (2004), highlighted the concern for practitioners between the crossover between 2 main issues – child protection and parental substance misuse. Guthrie identified the importance of the following legislation requirements in maintaining the safety of the substance misusers and their families:

- The Children (Northern Ireland) Order (1995);
- The Human Rights Act (1998);
- Protection Of Children And Vulnerable Adults (Northern Ireland) Order (2003);
- The Mental Health (Northern Ireland) Order (1986);
- The Northern Ireland Act (1998); and
- Data Protection Act (1998).

13.17 To conclude, care planning should be designed to facilitate the holistic needs of the women and the sharing of information from the multi-professional multi-agency services will be critical. This approach to care will only work with total collaboration from key workers and consent from the women to facilitate joint working.

13.18 The key areas of care are focused upon:

- primary health care;
- social services – Family and Child Care;
- midwifery services; and
- specialist drug and alcohol services.

13.19 Joint training should enable all multi-professional team members to recognise the importance of each other's role and the diverse parameters of each other's professional boundaries. Training should include all health and social care professionals. The key to the delivery of this service for the pregnant substance misuser should be the safety of the most vulnerable, namely the unborn child and other children within the family (Advisory Council on the Misuse of Drugs, 2003).

Recommendations

84. A detailed needs assessment should be undertaken within Northern Ireland to ascertain the extent of substance misuse among expectant mothers.

85. There should be development and support of the interagency services that are available to care for pregnant substance misusers and their families.

86. Specialist training should be provided for all members of the various agencies involved in the delivery of services.

87. Midwifery services should facilitate more accessible and non-judgemental services. Midwifery services and training should develop closer links with the community addiction services. These services should further develop the level of care given to the pregnant substance misuser.

88. Social services are tasked with the safety of the mother and family and it is important that close links are maintained with the addiction services. Family and child care social workers are often the key players in the engagement and treatment of the pregnant misuser. Addiction awareness training is vital for this professional group.

89. Addiction services should develop training protocols to deal with this client group and establish closer liaison with the maternity services, with easier access to addiction services for those in contact with maternity services.

90. Multi-agency training programmes should be developed and supported as a means of developing better understanding within the professional groupings involved. Training needs require investment.

91. There should be development of outreach services for those pregnant women who are unlikely to use formal provision (young people and the homeless).

92. Health education programmes and other preventative programmes need to target the areas of sex education and education on drugs and alcohol for young people.

93. Women who are pregnant should routinely be asked at booking about their use of tobacco, alcohol and drugs. Health advice should be offered.

CHAPTER 14

FAMILIES

INTRODUCTION

14.1 The consequences of continuous substance misuse impact on most families at some point. Substance misuse may occur in any or all family members. When examining the effects of substance misuse on families, it is appropriate to explore the interpersonal, physical, sociological, psychological, emotional, cultural and demographic factors relevant to the context in which the substance misuse takes place.

14.2 Tunnard (2002) reviewed the impact that substance misuse can have on the lives of children and their families. Reviewing findings from Britain, Ireland and America, she detailed how parental substance misuse impacted negatively on the family living situation, family and social relationships, behaviour, health and education.

14.3 Devaney (2004) has conducted research into childcare proceedings and the influence of substance misuse. He showed that alcohol was a concern in approximately 20% of cases where children had their name placed on the child protection register in Northern Ireland. He detailed that the 2 main research findings regarding the impact of parental substance misuse were:

- poorer developmental outcomes (physical, social and emotional); and
- higher risk of developing alcohol and drug problems in their own right compared to other children.

14.4 Within Northern Ireland, young people's drinking has impacted on domestic violence, street violence, child welfare, drink driving and anti-social behaviour. Families and communities often have difficulty in mounting the appropriate response.

14.5 Kenny (2003) noted that most professionals recognised the importance of family counselling/therapy within Northern Ireland. Provision of statutory services within this realm was noted to be patchy and inconsistent across Northern Ireland due to a lack of resources to support treatment services.

14.6 Responding to the needs of individuals and families dealing with the issues of substance misuse requires intervention and support at many levels. People are unlikely to change their substance misuse pattern unless they make a positive decision to do so. If the user does not wish to change in response to declining health or in response to the needs of others, this can be frustrating and difficult to understand for relatives and professionals who try to provide support.

14.7 The key messages from the report "Hidden Harm" (2003) compiled by the Advisory Council on the Misuse of Drugs are listed in Chapter 13 of this report. Many of the recommendations relate to supporting families and their children and detail specific issues for both addiction services and services for children and families.

Family Therapy

14.8 Systemic family therapy may be used to reduce the levels of stress and symptomatology in families. McDonald (2003) suggests the aims of such therapy are to:

- help the drug user to reduce his drug use and its consequent effects;
- improve family functioning; and
- reduce the problems of family members.

14.9 Such therapy is time consuming, requires involvement of the whole family and requires a high level of expertise from therapists. It is an appropriate approach to use for adolescents with substance misuse problems.

Primary Care Support for Families

14.10 General practitioners are often the first port of call for families. Orford (1999) has tested a model for primary care intervention with families of substance abusers in England. The emphasis is on appropriate knowledge and skills training for general practitioners with a view to improving family support.

Individual Counselling

14.11 Individual counselling may be given to family members where the spouse, relative, parent or child is abusing substances. This is the most common method of providing emotional support to family members. Provision of such a service requires adequate resources.

Family Support Group

14.12 Family support groups offer a wide range of services to families including: advice and information, advocacy, respite care, childcare, treatment assistance, counselling, drop-in facilities and help lines.

14.13 Family support groups reduce the need for professional involvement and members find reassurance through their common experiences.

14.14 The needs of all family members may not be addressed due to concerns about anonymity which may pose a barrier for some relatives seeking confidential support.

Social Services Support

14.15 Social Services are perceived by service users as only responding to families of substance misusers by enforcing child protection legislation. This can lead to unwillingness, particularly on the part of parents, to approach such services leading to under engagement. Research would suggest that parents who do engage regularly and meaningfully with counselling and treatment were the least likely parents to have their child made subject of a Child Care order (Cleaver et al. 1999, Klee 2002).

Recommendations

The recommendations are based on the DHSSPS (2003) draft report regarding substance misuse and the family.

94. The commissioning of addiction services should always include provision for carers and families.

95. All health and social care staff should be provided with specific training in substance misuse. The level of training will be relevant to the particular role and setting of work.

96. The recommendations from the Advisory Council on the Misuse of Drugs (ACMD) "Hidden Harm" report (2003) should be considered in a Northern Ireland context.

97. Information regarding dependant children in Northern Ireland should be incorporated within the Northern Ireland Drugs Misuse Database as recommended by the Advisory Council on the Misuse of Drugs (ACMD) "Hidden Harm" report (2003).

98. Evaluation and feedback regarding service provision should be sought from families and children. Families should be listened to, acknowledged and their experiences incorporated at all levels of planning and service provision.

99. Monitoring, evaluation and dissemination of best practice locally should be encouraged. Opportunities should be sought to develop innovative approaches to supporting families.

100. Joint approaches across children's and addiction services via the current children service plans should be extended throughout Northern Ireland.

CHAPTER 15

SMOKING

INTRODUCTION

15.1 Cigarette smoking remains the largest single preventable cause of death and disability in the UK, causing more than 120,000 deaths each year in people aged 35 or over (Raw et al., 1998), and costs the NHS an estimated £1.5 billion per annum in England alone. In Northern Ireland it is estimated that approximately 3,000 people die each year from smoking-related diseases, accounting for over 84% of all lung cancer deaths within the region (Callum, 1998).

15.2 Although smoking rates among adults have fallen over the last 15 years, this has not occurred to the same extent in lower socio-economic groups (W.H.O. Tobacco Free Initiative, 1999; Scientific Committee on Tobacco and Health, 1998), in which those suffering from mental illness largely fall. A relationship has been consistently demonstrated between psychiatric disorder and deprivation. Cigarette smoking has become increasingly concentrated in the most deprived groups.

15.3 The prevalence of smoking is far greater in those with mental health problems than the general population. Smoking prevalence in Britain among the general population is estimated at approximately 27% (British General Household Survey, 1998), whereas people with severe mental illnesses have been shown to smoke at twice the rate of the general population. In fact, it has been estimated that nearly 45% of all smokers in the United States are people with a "mental disorder" (Lasser et al., 2000).

15.4 In addition, smokers who have mental health disorders smoke much more heavily than other smokers. In an OPCS survey (Meltzer et al., 1995), over 50% of in-patients with schizophrenia were classed as heavy smokers (more than 20 cigarettes a day), and over ⅔ of people with schizophrenia smoked more than 25 cigarettes a day in a smaller Scottish study (Kelly & McCreadie, 1999). This compares to only 8% of the general smoking population who are reported to be heavy smokers of the same magnitude (Statistics on Smoking, 2000). Results from a study carried out in Northern Ireland (Jeffers et al., 2003) support and extend previous findings, and showed a smoking prevalence of 92% among a small hospital sample and 53% in a community sample.

15.5 Research evidence shows that specific psychiatric diagnosis can be associated with smoking behaviour, with the more clinically severe mental disorders having a greater prevalence and dependency (Lasser et al., 2000). This is most evident in institutionalised patients suffering from severe neurotic disorders and schizophrenia, where smoking prevalence has been repeatedly reported to be over 70%, and as high as 91% in those schizophrenia sufferers who are homeless and sleeping rough (Gill et al., 1996). Those with less severe mental disorders still consistently smoke more than the general population (McNeill, 2001).

15.6 A number of factors have been advanced to explain, at least in part, the high rates and severity of smoking among those with mental health problems. The most relevant explanations pertain to the influence of the environment and smoking as a self-medication. Also, there is an interesting debate about the direction of causality between smoking and mental ill health.

15.7 Extensive research supports the popular observation that 'smokers drink and drinkers smoke'. Moreover, the heaviest alcohol consumers are also the heaviest smokers. Between 80 and 95% of alcoholics smoke cigarettes and about 70% are heavy smokers (Patten et al., 1996). Several mechanisms may contribute to concurrent alcohol and tobacco use including genes involved in regulating brain chemical systems, neurobiological factors, conditioning mechanisms and psychosocial factors.

Impact of Smoking on Health

15.8 Considering the high rates of smoking, low income and passive lifestyles evident in people with mental health problems it is not surprising that many more people with mental health disorders die from smoking-related diseases, the rates of which can be twice as much in schizophrenics compared to age-matched controls (Brown et al., 2000). The severely mentally ill who smoke often have multiple morbidities and inadequate health care. Also, concurrent use of alcohol and tobacco poses a significant public health threat. A survey of people treated for alcoholism and other drug addictions showed that of deaths over a 12-year period ⅓ were attributed to alcohol-related causes and a ½ to smoking (Hurt, 1996). This impact of smoking on mortality and morbidity is largely unrecognised or unacknowledged by mental health services (Collinge, 2003).

Cessation Interventions

15.9 Smoking-related diseases are consistently the single most expensive outlay to the NHS and smoking directly or indirectly kills more people in western society than any other medium. Alleviating human suffering and managing the cost to society would therefore seem imperative, however, research shows that proven cessation interventions which are cost effective seem to be ignored institutionally. Treatment outcomes for patients addicted to both alcohol and nicotine are generally worse than for people addicted to only one drug, and many treatment providers do not promote smoking cessation during treatment for alcoholism. Recent findings suggest, however, that concurrent treatment for both addictions may improve treatment outcomes. An integrated smoking cessation strategy involving brief opportunistic advice from health professionals, pharmacological treatments and backed up by intensive specialist support is effective in promoting smoking cessation. The evidence base of the efficacy of these interventions has been reported in a Cochrane review (Lancaster et al., 2000).

15.10 These treatments are endorsed in the Tobacco Action Plan (2002), and recommended for various groups of smokers including disadvantaged adults such as those with mental health problems. However, there is some evidence (Lawn et al., 2002) that this group feels excluded from mainstream smoking cessation programmes. Many people with mental health problems have been found to be motivated to stop smoking. McNeill (2001) reports around half of smokers with mental health problems in British surveys expressed a desire to quit, and in North America studies show that people with schizophrenia recognize that smoking is a problem, are motivated to quit and are interested in attending smoking cessation groups. Addington et al (1998), also found strong motivation to quit among patients with schizophrenia, but concluded that unfortunately the symptoms and cognitive and social deficits associated with schizophrenia made participation in existing smoking cessation programmes difficult.

Environment and Policy

15.11 Mental health facilities have presented a particular challenge to tobacco control policies in the NHS. Staff do not raise smoking as an issue nor indeed assess patients' smoking status. Goldsmith (1993) suggested that the fear that patients would refuse admission to a facility that prohibits smoking and resistance from staff who smoke appear to be the major barriers to adopting a smoke-free policy. However, mental health professionals are well placed to intervene in the smoking behaviour of clients, to at least routinely ascertain clients' smoking status, provide educational materials and offer individual counselling. This in turn would represent a change in the prevailing culture around smoking in mental health facilities. Social attitudes as well as legislation and public health measures have been shown to influence changes in tobacco use (Lancaster, 2000).

Conclusion

15.12 The study of smoking among mental health service users in Northern Ireland (Jeffers et al., 2003) concluded with a number of recommendations for mental health services provision to include policy changes, specific therapeutic interventions and support structures to promote smoking cessation. These are set out in Annexe 15.

Recommendations

101. In both hospital and community mental health facilities the smoking status of clients should be ascertained at the time of assessment and monitored thereafter by mental health and primary care services.

102. All mental health staff should be trained to offer brief advice to clients at a stage when they are likely to be receptive to its import.

103. A staff training programme should be instituted to address staff attitudes to smoking and their own knowledge about smoking and mental health.

104. Specialist staff should be appointed to plan support services for smoking cessation aimed at those with mental health problems.

105. Staff training would also include counselling skills, group leadership skills and a full knowledge of the evidence base related to smoking and cessation methods. It should also include knowledge of the likely barriers to access smoking cessation services by these clients.

106. Health promotion leaflets and particularly those on smoking, and other cessation materials should be readily available in facilities accessed by people with mental health problems including primary care services.

107. Nicotine Replacement Therapy (NRT) or other pharmacotherapies should be prescribed as required as part of a cessation programme with specialist support. This is important as there is evidence that some people with mental health disorders continue to smoke in conjunction with taking NRT and so experience distressing effects.

CHAPTER 16

THE WIDER ENVIRONMENT – HOMELESSNESS AND EMPLOYABILITY

HOMELESSNESS

16.1 An audit was carried out by the Information and Research Working Group (part of the Joint Implementation Model of the Drug and Alcohol Strategies) in 2003 of identified homeless individuals with an alcohol or drug problem. The overall aim of the audit was to provide a detailed account of substance misuse among homeless people that could be used to inform future prevention and treatment activity. The methodology and detailed findings of the research are found in Annexe 16. This audit demonstrated that substance misuse is a significant issue among homeless people both in terms of prevalence of use and dependency. The use of substances was associated with high risk behaviours among the homeless population and the incidence of mental ill-health among homeless substance misusers. Most drug and alcohol use preceded homelessness and there was a strong connection between age of first substance use and the age of first homelessness, however some people began to use substances after they became homeless and it is clear that some individuals develop homelessness without ever having a history of substance misuse.

16.2 The audit showed a high level of risk behaviour in the homeless group reporting substance use. 50% of these reported suicidal behaviour and practice of unsafe sex. 40% each were involved in criminal behaviour and self-harming behaviour. 15% of the sample had been tested for blood borne diseases suggesting their involvement in injecting behaviour that put them at risk. Only 3 of the 154 homeless people reported current engagement in intravenous drug use. There was a high incidence of ill health in the sample. Some 35% had a diagnosed mental health problem and 22% were receiving treatment for a mental health problem.

16.3 Despite the high levels of problematic substance use in this population, few interviewees had access to substance misuse services. It appears for this group the priority is to secure accommodation as a key to stabilising other life issues, rather than to address the drug and alcohol problem as a primary issue.

16.4 Homeless people expressed strong views that the substance misuse and homelessness services should be improved to better meet the range of needs in terms of the range and specialisation of services available, they also commented on the lack of information provided on services and the ability of staff to deal with both problems simultaneously. Prevention was stressed by those interviewed as an important issue to address. Interviewees suggested that information should be available to educate people on the harmful effects of drugs and alcohol as well as information about services available.

16.5 The population sampled was much more likely to have accessed homelessness services rather than treatment services for drug and alcohol use. Despite this, almost 50% of the sample reported problems in accessing homelessness services and some of these access problems related to their substance misuse (for example the hostel policies on substance use). The homelessness providers confirmed that substance misuse is a key factor in accepting clients and in exclusions. Only half of the providers responding to the survey had staff who were trained to deal with substance misuse issues.

16.6 In addition, providers confirmed the negative impact of homelessness on successful treatment for drug and alcohol use.

16.7 This is a difficult group of people for the drug and alcohol services to engage. The priority for this group in accessing the homelessness services suggests that they should be targeted specifically for drug and alcohol interventions within these settings. At present the policies and strategies of the various organisations are not well integrated, despite a number of joint policy and working structures already in existence; these include PSI Working Group on Homelessness, Homelessness Strategy Partnerships and Supporting People Partnerships. Structures should be developed to integrate housing, homelessness and substance use services both from the preventive and the reactive perspective. Those who are potentially homeless should also receive support and mechanisms should be put in place to ensure early intervention that prevents such individuals becoming homeless. There are training implications for staff dealing with homeless people as well as staff in the adult substance misuse services. Some level of joint staff training may be appropriate.

Employability

16.8 Many people in treatment for substance misuse have multiple physical and mental health problems which impact on their capacity for optimal occupational function. Comprehensive functional assessment of these individuals is required so that specific interventions may be provided to achieve full potential in the areas of self-care, leisure and productivity. The use of purposeful activity as an intervention is valuable in identifying clients' personal resources. Participation in leisure and vocational activities has a clear impact on the individual's self-esteem and confidence, promoting community integration and social inclusion.

16.9 Initially, in leisure activities, individuals explore and identify their values and interests and include these in their developing routines. They can experience alternative means of structuring their time, making new social contacts, and positive feelings. There is a clear link between successful occupational participation and increased self-esteem and confidence. Other areas which benefit from structured rehabilitation approaches to occupational success and support occupational involvement are: healthy and productive daily living routines, resumption of positive life roles, improved sense of competence and self-esteem, increased confidence, time management, self-motivation, goal setting skills, the ability to manage negative emotions such as depression, anxiety and anger, and balancing productivity and leisure. It is important to recognise the essential role that leisure, vocational rehabilitation, life skills, work and training play in sustaining recovery from substance misuse and preventing relapse.

16.10 It may be that paid employment is an unrealistic or extremely long term goal for an individual with a substance misuse problem, and it should be recognized that there are a variety of successful occupational outcomes which may be valued by the individual. These might include variations of paid employment such as therapeutic work, supported employment, or part-time work, but there is a need to recognize and value volunteering, home-care, full or part-time education, caring for others and community involvement.

16.11 For many the pathway towards realizing their individual potential will progress through the above until the goal is achieved.

16.12 Four stages on the pathway towards employment are identified by the EIU, (2003), and support is vital through all these stages:

- employability development and prevocational training;
- work experience;
- transition into the labour market; and
- in-work support.

16.13 The EIU Guide to Working in Partnership (2003) identifies 3 main categories of providers of support that should work in partnership to maximize opportunities for clients:

- treatment and rehabilitation services;
- specialist employability programmes; and
- mainstream education.

16.14 Specialist occupational rehabilitation is poorly developed within current treatment provision, and specialist employability programmes for those recovering from substance misuse problems in Northern Ireland have no central co-ordination.

16.15 The Department for Employment and Learning (DEL) through its welfare reform and modernisation programme seeks to address the employability needs of its customers, particularly those who are furthest from the labour market. This includes people who have difficulty in obtaining work due to a history of drug misuse, alcohol misuse, homelessness and having a criminal record. This work has been informed by a series of focus groups carried out by DEL, as well as developments within the Department for Work and Pensions (DWP) and Jobcentre Plus in Great Britain. In relation to improving the work prospects of those with drug and alcohol misuse problems, the homeless and ex-offenders, a new service is proposed. This will provide specialist employability support for people who claim working age benefits and who experience significant difficulty in accessing jobs as a result of having a history of drug misuse or alcohol misuse.

16.16 The specific aim will be to encourage use of the new service on a voluntary basis by those in need and encourage the transition to employment, training or further education. There is some evidence that employment or employment related activity can aid the recovery process from substance use.

16.17 Many people recovering from drug and alcohol misuse face particular issues when they attempt to gain employment. Such issues include stigma, the benefit system, recruitment procedures, chequered work histories, a lack of existing qualifications and skills, health issues and treatment restrictions such as substitute prescribing regimes.

16.18 There is progress yet to be made in terms of sharing information and good practice, replication of successful approaches, communication between agencies, and creations of pathways through the agencies. Many models of partnership working already exist in other specialties, e.g. the Job Clinic model, which could easily be adapted for this client group.

Recommendations

108. The issue of substance misuse among homeless people should be addressed strategically.

109. Joint protocols between homelessness services and community addiction services should be encouraged. Integrated planning should be undertaken.

110. Staff working in the homelessness sector should receive training in the care, management and support of people with substance misuse problems.

111. Staff working in the addiction services should have training in homelessness issues.

112. Harm reduction techniques should be disseminated within the homelessness services.

113. Substance misuse services should focus on employability for all their clients.

114. There should be central co-ordination of agencies providing employability and rehabilitation services for clients who have been misusing substances.

115. A partnership approach should be encouraged between treatment provider services and agencies which encourage workplace rehabilitation and employment.

Annexes

Vision, Principles, Process and Challenges - Annexe 1

The Process

Membership of the Alcohol and Substance Misuse Working Committee (the Committee) was drawn from the relevant professional groups, the relevant statutory and voluntary providers of services, users and carers groups and from the established first wave working groups of the review process. Further nominations were sought from the Steering Committee of the Review of Mental Health and Learning Disability. A full list of members follows.

In addition, some people were co-opted to work with the Committee on specific issues. Their level of expertise was usually the reason for the choice of the particular individual. Their names and the areas in which they have made considerable input are also listed. The Committee extends our grateful thanks to these individuals, many of whom made a considerable work input to the process.

The Committee is one of the second wave of working committees of the Review of Mental Health and Learning Disability. It was formed in September 2003 with a view to delivering on the vision and principles of the overall review within the area of alcohol and substance misuse by December 2005.

The field of alcohol and substance misuse is wide. A range of substances are involved. Individual substances have not been the focus of this review, but rather the experience of addiction or misuse of a substance or several substances by the individual.

We must acknowledge that the substance of misuse is important to the individual, as is its means of supply; for example it may be a prescribed medication, it may be an over the counter preparation, it may be a substance which was provided on prescription for another named individual, it may be purchased on the “black market” or it may be a commodity which is used as “currency” in order to coerce the individual to carry out certain behaviours. In the case of illicit drugs, the criminal behaviour which accrues from drug seeking behaviour may have greater adverse consequences than the mental health or other health consequences of drug use in itself. These matters have not come within the scope of this review.

The very wide range of treatment levels from the “early interventions” so successfully employed within alcohol counselling to the very intensive, intrusive interventions developed within the most highly specialist centres have formed part of the scope of the Review and are clearly dealt with within the early chapters.

The wide range of constituent groups within our population who are entitled to drug and alcohol misuse services also very properly constitutes the scope of the Committee. The needs of the constituent groups are diverse and varied; for example young people do not at present enjoy a comprehensive service for their drug and alcohol treatment needs. Those with learning disability also receive a poor and "patchy" range of services, often because of difficulties in accessing existing services, across the spectrum. We have addressed these issues in Chapters 8 onwards.

Because of the diverse needs of the constituent groups of people in need of drug and alcohol services, we have drawn our user involvement from reference groups of service users and of specifically selected individuals within the community targeted because of perceived need, rather than attempting to have "representation" of a diverse group of service users views. The information collected from these reference groups has been given considerable weight in this document. In particular, the views of those not currently accessing services or in receipt of services for alcohol or substance misuse, but perceived to be in need, have been given weight.

We have sought the views of members of the public, service users, designated "experts" in several areas of substance misuse, provider organisations within the statutory, voluntary and community sectors and the universities. Representatives from all of these sectors have made presentations to the Committee and in several instances have provided examples and contributions to our treatment framework. We have also sought specific input from Probation Board of Northern Ireland (PBNI) and Department of Education and Learning (DEL).

We are very grateful for the considerable help and input given to the Review by these organisations. We are deeply grateful to individuals who made presentations to the Committee for consideration.

The views of the Review Steering Committee have also been useful throughout the process of development of this treatment framework.

We were delighted to receive so many written responses to the original consultation document. The consultation process for children led to particular concern among some of those consulted. For this reason, a further focus group of young service users was approached for specific consultation and the results of this can be seen at www.rmhldni.gov.uk

An additional area of concern was the involvement of service users with "dual diagnosis" – the concurrent presence of severe and enduring mental illness and substance misuse. The service user group of the Review facilitated a focus group on this topic. The process can be viewed at www.rmhldni.gov.uk

Members of the Alcohol & Substance Misuse Working Committee:

Dr Diana Patterson (Chair)
Dr William Gregg
Professor Robin Davidson
Ms Anne-Marie McClure
Mr Martin Milligan
Mr Rob Phipps
Mrs Briege Quinn
Mr Owen O'Neill
Mrs Mary McTaggart

Dr Rick Anderson
Ms Nuala Cassidy
Dr Dominic Connolly
Ms Pauline McDonald
Dr Pam McGucken
Dr Ita Mulholland
Dr Lawrence Taggart
Dr Carol Weir

Co-Opted Contributors:

Dr J Hynes - Young People
Dr N McCune - Young People
Ms M Davren - Young People
Dr O Shanks - Learning Disabilities
Mr A Coleman - Old Age
Mr A Guthrie - Families
Ms K Jeffers - Smoking and Mental Health
Mr D Carroll - Homelessness

Mr Barry McCrory - Secretariat

The Current Position – Annexe 2

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Voluntary & Community Organisations – Annexe 3

Self Help Organisations

Alcoholics Anonymous (A.A.) is a prime example of a self-help organisation. A.A. has become much more accepted by clinicians and academics over the past 10 years or so. There are a number of reasons for this, most notably the findings of project MATCH (1997). An intervention based on the 12 steps was found to be as effective as motivational enhancement and cognitive psychotherapy in this the largest alcohol treatment study ever conducted. After decades of virtually no 12 step outcome studies we now have more data from both the United Kingdom and USA (Best and Harris 2000, Tonigan et al., 2000). While the evidence for A.A. as a stand alone treatment for alcohol dependence remains weak, these studies seem to demonstrate that involvement with A.A. can improve outcome for those who are discharged from formal treatment programmes. A.A. can now be regarded as a mainstream legitimate aftercare option.

Drug Misuse Database Returns

The funded voluntary services range from small local community groups to large established organisations. Some groups rely on very little income and others are core funded by the Department of Health, Social Services and Public Safety (DHSSPS).

Data collection by the Northern Ireland Drug Misuse Database (DMD) commenced in 2000. Initially only 10 agencies – 6 statutory and 4 non-statutory, agreed to contribute to the database. By 2003-2004, 55 treatment sites were contributing to the database, 26 of which were non-statutory including 3 services based within prisons. In 2004, 47% of those listed on DMD's presented to non-statutory agencies. This varied across Northern Ireland with 69% in the Eastern Health and Social Services Board, 25% in the Northern Health and Social Services Board, 32% in the Southern Health and Social Services Board and 20% in the Western Health and Social Services Board.

These figures in 2004 reflect a growing development of voluntary and community based services. DMD documents 16 non-statutory separate, projects and 16 further projects in partnership between voluntary, community and statutory services, including 2 partnerships with the prison service. There may be agencies in the voluntary and community sector who solely deal with clients with an alcohol misuse problem who would not be contributing to the DMD returns.

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Community & Primary Care Settings – Annexe 4

Models of Care for Treatment of Adult Drug Misusers

The National Treatment Agency (NTA) is a special health authority, created by the Government, with a remit to increase the availability, capacity and effectiveness of treatment for drug misuse in England. The NTA has produced models of care for treatment of adult drug misusers. This document is in 2 parts, the first summarising information for Drug Treatment Commissioners and those responsible for local implementation and the second part providing a detailed reference document for Drug Treatment Managers and providers. The documents are available at www.nta.nhs.uk The document was printed in October 2002.

Models of Care sets out a national framework for the commissioning of adult treatment for drug misuse which is expected to be available in every part of England to meet the needs of diverse local population. This is an integrated system across a large geographic area. The models described include the statutory and non-statutory services and encompass delivery at primary and secondary care levels.

An important principle described by the HealthAdvisory Service in 1996 is that each local area should have equal access to a full range of services. It is accepted within Models of Care that not all drug and alcohol users require all services or all tiers of the services. Strategic commissioning should take note of the effects of all parts of provision. For example, in planning new services, the effects of these across all of the tiers must be taken into account. The aspiration is that clients should be able to move in a "seamless" way between different parts of the systems and between different levels of involvement.

There are 4 key domains of treatment. These are:

1. **Drug and Alcohol Use**

   - drug use including type of drugs, quantity/frequency of use, pattern of use, route of administration, source of drug; and

   - alcohol use including quantity/frequency of use, pattern of use, whether above "safe" level, alcohol dependence symptoms.

2. Physical and Psychological Health

- psychological problems including self harm, history of abuse/ trauma, depression, severe psychiatric co-morbidity, contact with mental health services; and
- physical problems including complications of drug/alcohol use, pregnancy, blood borne infections/risk behaviours, liver disease, abscesses, overdose, enduring or severe physical disabilities.

3. Social Functioning

- social problems (including childcare issues, partners, domestic violence, family, housing, employment, benefits, financial problems).

4. Criminal Involvement

- legal problems (including arrests, fines, outstanding charges/ warrants, probation, imprisonment, violent offences, criminal activity).

The Models of Care framework recommends commissioning for Drug and Alcohol Services across a 4-tiered framework.

Tier 1

Non Substance Misuse specific services requiring interface with drug and alcohol treatment. Tier 1 services work with a wide range of clients including drug and alcohol misusers but their sole purpose is not drug or alcohol treatment. The role of Tier 1 services in this context includes the provision of their own service plus as a minimum screening and referral to local drug and alcohol treatment services in Tiers 2 and 3. Tier 1 service provision may also include services to reduce drug related harm and liaison or to joint working with Tiers 2 and 3 specialist drug and alcohol treatment services.

Tier 2: Open Access Drug and Alcohol Treatment Services

Tier 2 services provide accessible drug and alcohol specialist services for a wide range of drug and alcohol misusers referred from a variety of sources. This tier is defined by having a low threshold to access services and limited requirements on the drug and alcohol misusers to receive services. Often drug and alcohol misusers will access drug or alcohol services through Tier 2 and progress to higher tiers.

Tier 3: Structured Community Based Drug Treatment Services

Tier 3 services are provided solely for drug and alcohol misusers in structured programmes of care. These services include psychotherapeutic interventions, for example, CBT, motivational interventions, structured counselling, methadone maintenance programmes, community detoxification or day care. Community based aftercare from residential rehabilitation or prison is also included in Tier 3 services. Tier 3 services require the drug and alcohol misuser to receive an assessment and have a care plan which is agreed between service provider and client. The client will normally have agreed to a structured programme of care which places certain requirements on attendance and behaviour.

Tier 4: Residential Services for Drug and Alcohol Misusers

Tier 4a: Residential drug and alcohol misuse specific services:

These services are rarely accessed directly by clients. Referral is usually from Tiers 2 or 3 services via a community led assessment. These services usually require a higher level of commitment from drug and alcohol misusers than is required for services in lower tiers. Tier 4a services may be abstinence orientated programmes, detoxification services or services which stabilise clients, for example, on substitute drugs. Access to Tier 4a requires careful assessment on the preparation of the client in order to maximise readiness compliance and programme effectiveness. By definition such programmes are highly structured. Drug and alcohol misusers receiving Tier 4 services will require assessment by a designated care co-ordinator.

Tier 4b: Highly specialist non substance misuse specific services:

Tier 4b services are highly specialised and will have close links with services in other tiers but are, like Tier 1, non substance misuse specific. Examples include specialist liver units that treat complications of alcohol related and infectious liver diseases and forensic services for mentally ill offenders. Some highly specialist Tier 4b services also provide specialist liaison services to Tiers 1 to 4a services (for example, specialist Hepatitis Nurses, HIV Liaison Clinics, Genito-Urinary Medicine).

The models of care document recommends that all drug and alcohol teams in England must have access to the following Tier 4 services, probably provided at a multi DAT or regional or national level:

- specialist Drug and alcohol residential rehabilitation programmes (including a range of 12 step, face based and eclectic programmes);
- generic and drug specialist semi structured residential care (for example, half way houses, semi supported accommodation);
- specialist drug treatment and testing order treatment (residential options);
- inpatient drug misuse treatment, ideally provided by specialist drug misuse units or alternatively by designated beds in generic (mental) health services;
- highly specialist forms of residential rehabilitation units or other residential services (inpatient, prison) with a drug misuse treatment component (for example, women and children, crisis intervention, dual diagnosis); and
- relevant Tier 4b services, including HIV or liver disease units, vein clinics and residential services for young people.

While the services for alcohol misusers are less well specified, Commissioners of alcohol services are advised to ensure that alcohol misusers have access to a range of Tier 4 services as appropriate.

Principles of the 4 Tier System

The 4 tiered model of drug and alcohol treatment for adults was developed from the 4 tier approach to a variety of mental health and drug misuse services for young people outlined by the Health Advisory Service in 1996. Principles which underpin these tiers include the recommendation that each local region should have equality of availability to the full range of services described in the Tier framework. Not all drug and alcohol misusers will require access to all types of services or all tiers, but within each locality a proportion will require access to each of these services at any given time. Access to all services should therefore be available in all areas in England. As the drug treatment services described within each tier are modalities, not specific agencies, it should be possible for one agency in a given locality to provide services located in more than one tier, or provide a range of modalities from within tiers. Some drug and alcohol misusers may require access to services within a number of different tiers simultaneously. For example, needle exchange services (Tier 2), structured counselling (Tier 3) and housing services (Tier 1).

Through the care plan, the care co-ordinator should facilitate access to a range of services based on client need.

Commissioners should recognise that motivational work may be crucial in engaging clients in drug and alcohol treatment and improving their outcomes in a number of domains. A service provider's ability to motivate a drug misuser is a greater factor in client success than the expressed motivation of the client (Fiorentine et al. 2000). Client motivation should not be used as an exclusion criterion, it should be a trigger for motivational work which should be commissioned and provided by each drug treatment provider. The use of the tiered system is helpful for clarifying the commissioning process and should enable commissioners to ensure equal access to all appropriate levels of treatment for all of the population they serve.

The Models of Care document recommends the use of integrated care pathways. An integrated care pathway describes the nature and anticipated course of treatment for a particular client and a predetermined plan of treatment. Any system of care should be dynamic and able to respond to changing individual needs over time. It should also be able to provide access to a range of services and interventions that meet an individual's needs in a comprehensive way. Drug and alcohol misusers often have multiple problems which require effective co-ordination. Several specialist and generic service providers may be involved with one client over a spell of time. Each drug and alcohol treatment modality should have an integrated care pathway.

Such pathways should have the following elements:

- a definition of the treatment modality provided;
- aims and objectives of the treatment modality;
- definition of the client group served;
- eligibility criteria (including priority groups);
- exclusions criteria or contra-indications;
- referral pathway;
- screening and assessment processes;
- development of agreed treatment goals;
- description of the treatment process or phases;
- care co-ordination;
- departure planning, after care and support;
- onward referral pathways; and
- services with which the modality interfaces.

This integrated care pathway approach allows commissioners to map the whole care system in localities so that gaps and overlaps can be identified and rectified via the commissioning process. It also provides a means of agreeing local referral and treatment protocols to define where and when particular clients should be referred.

Residential Provision & Rehabilitation – Annexe 5

Research Evidence Base for Inpatient Treatments

Research suggests that a high proportion of patients accessing inpatient treatment can achieve successful withdrawal from opioids for example, Gossop et al., (1989) found that 51% of patients in England, treated in a Specialist Inpatient Unit were drug-free at 6 month follow-up. A controlled study of inpatient versus outpatient treatment of opiate withdrawal in the United Kingdom found inpatient withdrawal to be 4 times more effective in terms of the proportion of patients who completed the withdrawal regime (Gossop et al., 1986). There is evidence that a dedicated Substance Misuse Inpatient Unit is associated with better outcomes in terms of completion of opioid withdrawal and abstinence from opioids after 7 months than a General Psychiatric Ward (Strang et al., 1997).

Strong evidence has emerged from the National Treatment Outcome Research Study (NTORS) that clients admitted to Residential Treatment Programmes showed substantial improvements in terms of abstinence from opiates, psycho-stimulants and benzodiazepines (Gossop et al., 1998). At 1 year, more than ⅓ of all patients admitted to Residential Treatment Programmes were abstinent from all of the target drugs and had been so for the previous 3 months. There were significant improvements in other problem areas including injecting, sharing, injecting equipment, heavy drinking and criminal behaviour. A critical period of 28 days for inpatient and a short stay residential programmes appeared to predict likelihood of achieving abstinence from opiates at 1 year, although improvements were also seen in patients who were discharged before this critical period (Gossop et al., 1999).

The studies report drop-out rates of between 18% - 46% (Ghodse et al., 1987, Gossop et al., 1987). Severe drug use and severe medical problems were identified as predictors of failure to complete inpatient detoxification in one study (Franken and Hendriks, 1999). Most of this work has been conducted on opioid users and there is little evidence pertaining to treatment of stimulant drug users in an inpatient setting.

A variety of medications have been found to be helpful in managing withdrawal syndromes in inpatient facilities. These include oral methadone, codeine-based medication such as dihydrocodeine and buprenorphine. Lofexidine may be used for opioid withdrawal and there is evidence that it is as efficacious as methadone in inpatient withdrawal (Bearn et al., 1996). Symptomatic relief of mild Opioid withdrawal symptoms, for example by the use of Diphenoxylate, Promethazine and Propranolol has also been described (Department of Health et al., 1999).

Concurrent addiction to opioids and benzodiazepines is common. The majority of opioid drug users presenting for treatment have a history of benzodiazepine use in the year prior to treatment and nearly ½ of opioid users in treatment have injected benzodiazepines (Perera et al., 1987, Strang et al., 1994). In 1 study, some 43% of patients who reported benzodiazepine use were found to be physically dependent on these drugs and were stabilised on a mean dose of diazepam of 40mg (range 20mg – 80mg) (Williams et al., 1996).

Sedative withdrawal is usually carried out with substitution benzodiazepines, usually using longer acting preparations such as diazepam (Ghodse, 1995). For drug users who are dependent on both sedatives and opioids it is recommended that benzodiazepine withdrawal be completed first while the patient remains on a steady dose of substitution opioid such as oral methadone.

There is little evidence for the use of substitution stimulant prescribing in the inpatient treatment setting. However there is a role for non-substitution prescribing for stimulant withdrawal in inpatient settings including the relief of symptoms such as anxiety, agitation and psychotic indications. Most studies of this field have found that a psychosocial abstinence based approach is most efficacious (Carroll et al., 1995).

The prescription of anti-depressant medication for major depressive episodes associated with stimulant use may also be appropriate.

Prescribing interventions for relapse prevention may be prescribed during inpatient treatment. Naltrexone, an opiate antagonist and Disulfiram which causes adverse effects with alcohol, have both been shown to have a solid evidence base and should normally be commenced in inpatient settings or day patient settings.

Bed Numbers

The Royal College of Psychiatrists recommends that there should be hospital bed provision for substance misuse of 3 beds per 100,000 general population. There should also be access to rehabilitation and recovery beds including beds for the significant minority of patients who are not suitable for non-statutory rehabilitation facilities because of dual diagnosis or complex needs. Beds should also be available for people with major physical health problems such as alcoholic brain damage or acquired immunodeficiency syndrome.

Staff Numbers

The Royal College of Psychiatrists recommends there should be 0.9 WTE Consultant Psychiatrists per 100,000 population, rising to 1.5 WTE per 100,000 population in urban areas. Nursing levels should meet Telford recommendations on analysis of individual wards. Benchmarks for other staff groups are lacking, e.g. occupational therapists and social workers. This area is addressed in the manpower document of the Alcohol and Substance Misuse Working Committee of the Review of Mental Health and Learning Disability. www.rmhldni.gov.uk

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Interface with General Hospitals - Annexe 6

A large number of screening instruments have been developed to help identify individuals who are misusing alcohol. The CAGE questionnaire is perhaps the best known alcohol screening instrument but it may be less sensitive than the AUDIT questionnaire in identifying individuals who are drinking alcohol at hazardous or harmful levels (5). The AUDIT (Alcohol Use Disorders Identification Test) is a 10 item self-administered questionnaire developed by the World Health Organisation. Scores of 8 or more is associated with harmful or hazardous drinking. A score of 13 or more in women, or 15 or more in men is likely to indicate alcohol dependence (6). Shortened versions of the AUDIT such as the FAST (Fast Alcohol Screening Test) may be useful where time for assessment is very limited, such as A&E Departments. The FAST consists of only 4 questions from the AUDIT which can be incorporated into routine history taking (7).

Brief interventions in Medical Patients with Alcohol Related Problems

A recent meta-analysis of opportunistic brief intervention for problem drinkers in a General Hospital setting found only 8 of a potential 481 papers as suitable for analysis. In only 1 of these 8 papers was there a significant benefit from the intervention in comparison to the control group. However the 7 negative trials all showed a significant reduction in alcohol consumption. The authors suggested that the act of carrying out even just an assessment of alcohol consumption in the control group may have been enough to encourage a reduction in alcohol intake (8).

Heather and Wallace concluded that the outcomes from brief interventions in a hospital setting have been disappointing in comparison to studies in primary care and that further work is needed to determine “what kind of intervention delivered in what ways can be effective” (9). More recent work has shown that for heavy drinkers admitted to hospital some brief opportunistic interventions may be useful. Alcohol dependent individuals are unlikely to benefit solely from brief interventions and they will usually require more intensive treatments.

Brief interventions can be delivered using a motivational interviewing approach opportunistically by non alcohol specialists usually in 1-3 sessions. The common elements of brief interventions have been described using the FRAMES model (Feedback, Responsibility, Advice, Menu of Options, Empathy and Self-efficacy) (10,11).

Management of delirium tremens and Wernicke-Korsakoff Syndrome.

Delirium tremens is a potentially life threatening condition which develops during withdrawal from alcohol in some heavily dependent individuals and requires treatment in a general medical hospital. It is characterised by symptoms include visual and/or auditory hallucinations, paranoid delusions and autonomic over-activity. Patients with delirium tremens can present major management problems in a medical setting. The full-blown syndrome can often be averted if appropriate treatment is instigated in a timely fashion.

Wernicke's encephalopathy is caused by acute thiamine deficiency and should be suspected in any patient with a history of alcohol misuse and any of the following symptoms or signs:

- confusion;
- Ataxia, especially truncal ataxia;
- Opthalmoplegia;
- Nystagmus;
- memory disturbance;
- hypothermia and hypotension; and
- coma.

Guidelines on the treatment of delirium tremens, and Wernicke's encephalopathy is available from a variety of sources (1,2,12,13,14). Benzodiazepines in adequate doses and parenteral thiamine (Pabrinex) are the mainstay of the pharmacological treatment of delirium tremens along with a high degree of nursing care in a non-stimulating environment. Any co-existing serious medical conditions such as a sub-dural haematoma, head injury, infection, electrolyte or metabolic disorders need to be promptly identified. It can be helpful to monitor the progress of the patient using an alcohol withdrawal scale, such as the CIWA-Ar.

Failure to detect and adequately treat Wernicke-Korsakoff syndrome may lead to long-term disability with persisting impairment in new learning and inability to maintain independent living.

Local Examples of Good Practice

Specialist Alcohol Liaison services are currently being piloted in the Ulster Community and Hospitals Trust and the Mater Hospital. Alcohol Liaison nurses are acting as key links between acute hospital staff, service users and local specialist addiction services. The staff will also play a significant role in the provision of training and support of general hospital staff in the recognition and management of alcohol and drug related problems.

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Harm Reduction Services for Injecting Drug Users - Annexe 7

Many harm reduction based programmes such as needle exchange schemes are of recent origin. Others however have a long history: methadone programmes for example date back to the 1960's and have demonstrated their effectiveness in assisting drug users to stabilise and normalise their lifestyles and to provide many with a bridge to abstinence from narcotic use (Bertschy, 1995). Around the 1980's, a number of countries introduced needle exchange schemes and developed or extended their methadone treatment programmes, subsequently leading to claims that these policies have been successful in averting or reversing the epidemic spread of HIV/AIDS (Stimson, 1996; Des Jarlais, 1996; Des Jarlais, 1998; Commonwealth Department of Health and Ageing 2002; Hunt, 2003). Weil (1972) acknowledges that, whilst carrying risks drug use also provides the user with benefits, as they view it, which must be taken into account if drug-using behaviour is to be understood. As such harm reduction fits comfortably with approaches that emphasise the importance of understanding the broad determinants of health and ensures effective approaches are in place for the well-being of the entire population.

Given the risks to the drug user and the community it is important that we fully understand why people choose to engage with services and address such risk issues and what we can do to encourage and retain injecting drug users in treatment. To address and understand the barriers and incentives to help seeking among the injecting drug using population evidence has emerged to suggest that service users require a more flexible approach to treatment offering more choice, a knowledgeable workforce and more intensive aftercare and practical support (Quinn & Foley, 2002).

Definition and Principles of Harm Reduction

"As a specific strategy, the term harm reduction generally refers to only those policies and programmes which aim at reducing drug-related harm without requiring abstention from drug use" (Conley et al., 1999).

Harm reduction attempts to recognise and remove judgements about drugs, drug use and drug users by treating each individual with dignity and respect. Harm reduction is neutral regarding the long-term goals of care interventions. Any reduction in harm is seen as a step in the right direction. Quality of life, social inclusion and mental and physical well-being are seen as criteria for measuring success not reduction in the consumption of drugs (Single, 1996). The Canadian Centre on Substance Abuse (CCSA) (1996) describes the main characteristics or principles of harm reduction as follows:

Pragmatism

Harm reduction accepts that some use of mind-altering substances is a common feature of human experience. It acknowledges that, while carrying risks, drug use also provides the user with benefits that must be taken into account if drug-using behaviour is to be understood. From a community perspective, containment and amelioration of drug-related harms may be a more pragmatic or feasible option than efforts to eliminate drug use entirely.

Humanistic Values

The drug user's decision to use drugs is accepted as fact. This doesn't mean that one approves of drug use. No moralistic judgment is made either to condemn or to support use of drugs, regardless of level of use or mode of intake. The dignity and rights of the drug user are respected.

Focus on Harms

The fact or extent of a person's drug use per se is of secondary importance to the risk of harms consequent to use. The harms addressed can be related to many factors affecting the individual, the community and society as a whole. Therefore, the first priority is to decrease the negative consequences of drug use to the user and to others, as opposed to focusing on decreasing the drug use itself. Harm reduction neither excludes nor presumes the long-term treatment goal of abstinence. In some cases, reduction of level of use may be one of the most effective forms of harm reduction. In others, alteration to the mode of use may be more effective.

Balancing Costs and Benefits

Some pragmatic process of identifying, measuring, and assessing the relative importance of drug-related problems, their associated harms and costs/benefits of intervention is carried out in order to focus resources on priority issues. The framework of analysis extends beyond the immediate interests of users to include broader community and societal interests. Because of this rational approach, harm reduction approaches theoretically lend themselves to evaluation of impacts in comparison to some other, or no, intervention. In practice, however, such evaluations are complicated because of the number of variables to be examined in both the short and long term.

Priority of Immediate Goals

Most harm-reduction programs have a hierarchy of goals, with the immediate focus on proactively engaging individuals, target groups, and communities to address their most pressing needs. Achieving the most immediate and realistic goals is usually viewed as first steps toward risk-free use, or, if appropriate, abstinence.

Research Evidence Base for Barriers and Incentives to Help Seeking for Injecting Drug Users

The barriers and incentives to help seeking may be multifactorial. More and more emphasis is being placed on the complex mix of social, psychological and environmental influences on people's engagement with health services. Such interactions require examination to establish how factors come together to form an individual's own experiences and give insight into why in this case injecting drug users make the choices they do.

A Northern Ireland based practice development research study used focus groups as the instrument to investigate, document and interpret the research data on barriers and incentives to help seeking (Quinn & Foley, 2002). The focus group members were nurses, doctors, social work and occupational therapy staff who provide treatment services for injecting drug users, former clients of treatment services and those injecting drug users who had chosen not to avail of the treatment services.

The researchers found that service providers perceived Injecting Drug Users (IDUs) as sophisticated clients in accessing services. They (IDUs) were also perceived as a more challenging client group than other addiction service users. There were concerns that the needs of the alcohol user could be 'lost' in any concentration on IDUs.

Viewpoints were strongly supportive of the development of a Harm Reduction Service for IDUs, widening the range of interventions for clients and reducing harm to the community. A consensus agreed that the development or acquisition of knowledge and skills would:

- improve treatment effectiveness; and
- improve workers confidence.

Workers indicated training needs for specialist skills and knowledge in working with clients on issues such as blood borne viruses, particularly pre and post test counselling/discussion and in harm reduction techniques such as safer injecting. Training on working with substitute prescribing was also identified. In his review of harm reduction approaches Hunt (2003) points to best practice issues including promotion of blood borne virus investigations, skills and knowledge, service user involvement in service development and low threshold diverse services from agencies with harm reduction values and culture.

Service users felt that their expressed needs were often unresolved, e.g. in detox processes they felt staff didn't adequately medicate for their symptoms. They perceived a lack of involvement in their care planning, wanting to feel more included, and avoid inaccurate planning as they pointed to some unrealistic expectations of addiction workers - e.g. attending for medication at appointments early in the morning under circumstances of withdrawal. Marlett et al (1996) indicated that barriers and incentives to help seeking should be interpreted in terms of behavioural economics, moving the focus from agencies to individuals, from service providers to service users.

Service users felt that drug workers lacked insight into drug users experiences and that a broader, client centred approach should be adopted, preferably in a separate service from abstinence based addiction services with options of longer term residential rehabilitation. Residential rehabilitation offers intensive and structured programmes delivered in controlled residential, hospital inpatient or other controlled environments. The NT ORS study (Gossop et al., 2001) found at 5 year follow up that the outcomes in residential treatments with a duration of 10 weeks stay were at least as good as outcomes with community treatment programmes. Guidance on residential rehabilitation services is provided by the National Treatment Agency (DHSS 2002).

Service users described occasions when they felt rejected by primary care staff when asking to be taken on as their patients. Drug users attending primary care services in a study (McLaughlin et al., 2000) also identified a perceived negativity from this group.

They felt that trained and skilled staff, knowledgeable in harm reduction techniques and approaches could help address the negative perceptions and misconceptions around their chronic relapsing condition.
They concluded by recommending:

- a more flexible approach to treatment offering more choice, e.g. substitute prescribing, outreach and choice of inpatient/outpatient detoxification;
- residential rehabilitation lasting up to 6 months; and
- more intensive aftercare and practical support.

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Children and Young People - Annexe 8

Models of Care Principles

"All young people's drug treatment services should be developed in line with the Standing Conference on Drug Abuse and the Children's Legal Centre (1999) ten key policy principles, as outlined below. As a matter of good practice these should inform and underpin the development of drug services for young people" (National Treatment Agency, 2004, pg 137):

- a child/young person is not an adult;
- paramouncy of the child/young person is of utmost importance in accordance with the Childrens Order 1990 and the UN Convention of the Rights of the Child 1989;
- the views and opinions of the child/young person should always be sought and considered;
- parental responsibility should be respected;
- services should be available to children/young people in their local area;
- a holistic multi-agency approach to the diverse needs of children/young people at all levels is vital;
- all services must be child/young person centred;
- the range of services provided for children/young people requires to be comprehensive;
- services must be competent in responding efficiently and effectively to the diverse needs of children/young people; and
- principles of good practice should inform the planning and delivery of services to children/young people.

Health Advisory Service, Substance of Young Needs 2001

Staff working with under 18s should know and be able to demonstrate where appropriate the following levels of skills:

Level 1 – General Training Core Knowledge, Attitudes and Skills:

- basic knowledge of physical, psychological and social effects of drugs and alcohol including parental drug use;
- knowledge on cultural effects, age, religion, gender, and patterns of use;
- awareness of practitioner's own attitudes to drugs and alcohol.
- basic life support skills;
- recognition of drug and alcohol use and its related problems;

- the ability to provide accurate information about drugs, alcohol and other substances; and
- information and advice about services and their referrals criteria to individuals.

Level 2 – More Advanced Training:

- communication and counselling skills for young people and their families;
- assessment skills, of risk, of substance-related problems, of child's developmental needs;
- ability to assess individual's need for care and their prioritisation;
- deliver services according to protocols based on evidence of what works;
- support for carers of substance users;
- knowledge of the legal aspects, e.g. competence of the child to consent, confidentiality, local child protection guidelines;
- skills in recording contemporaneous details and monitoring of treatment effects; and
- deliver evidence based universal education and prevention programmes.

Level 3 – Specialist Training:

- in-depth knowledge of child and adolescent development and the impact of negative events, of risk and protective factors and mental health issues;
- multi-disciplinary skills, including joint working with other agencies and with parents and children;
- comprehensive assessment of the impact of substance misuse, of developmental issues, of mental and physical health and child protection;
- ability to deliver comprehensive and continuing programmes of care in liaison with other workers and agencies;
- review care provided to individuals; and
- ability to work within the child protection guidelines.

Health Advisory Service (HAS) Model

It is now generally accepted that the HAS 4 Tier model first outlined in 1996 should be used when planning substance misuse services for young people. The majority of services in Northern Ireland operate mainly at Tiers 1 and 2 and include primary care, health and social services, education, criminal justice and the voluntary and community sector. All of these services provide information and support to young people on drug and alcohol issues.

Tier 1 – Generic and Primary Services:

The front line of service delivery to which children, young people and their families have direct access and which provide the first response to the needs of children and adolescents. Examples of such services include schools providing substance misuse education and primary care services offering medical advice.

Tier 2 – First Line of Specialist Services:

Front line young people's specialist services are critical to the identification of vulnerable children and early identification. Their roles should be concerned with the reduction of risks and vulnerabilities to substance misuse, and the reintegration and maintenance of young people in mainstream services. Examples of such services include social services assessing substance misuse among looked after children, voluntary agencies providing counselling services and criminal justice agencies addressing offending issues.

Tier 3 – Services Provided by Specialist Teams:

A multidisciplinary team demonstrating a threshold of expertise and competence that is capable of comprehensive assessment and formulation of an overall plan for substance use and various other problems, including outcome domains. The team will deal with the complex and often multiple needs of the child or young person, including substance problems. The aim is to reintegrate and include the child or young person into his/her family, community and school, training or work. Examples of such services may be stand alone services either within the voluntary or statutory sector or specialist services integrated across CAMHs.

Tier 4 – Very Specialised Services:

Very specialised children and young people's services used for particular interventions or focused work and/or short/temporary periods. This might consist of inpatient adolescent services or forensic units complemented by specialist young people's addiction teams, paediatric beds or intensive day centres for detoxification, crisis placements, specialist housing or fostering. The aim would be to provide specialist interventions and a setting for a particular period of time, and for a specific function, as an adjunct to and a backstop for the services for other tiers.

Continuity of care pre, during, and post admission is important, the development of a Through-Care model would facilitate this.

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People with Learning Disabilities - Annexe 9

Prevalence of Substance Misuse

'Substance use' in people with learning disabilities is generally reported to be less common than in the general or psychiatric populations across both sides of the Atlantic. 'Substance abuse or misuse' in people with learning disabilities has also been reported to be less common than in the non-disabled population (Huang, 1981, Christian & Poling, 1997, Annand & Gug, 1998, Burgard et al., 2000, Havercamp & Scandlin, 2002, Sturmey et al., 2003).

There is variation in the reported prevalence rates in people with learning disabilities who misuse alcohol and drugs. Discrepancies centre upon methodological problems often associated with the lack of clear operational definitions of 'misuse', the methodology employed, the level of learning disability, location, the time-frame and whether persons are known to learning disability services or not. Sturmey et al. (2003) stated that "it is difficult to define any consensus …., however, prevalence rates may vary somewhere between 0.5% - 2% of this population" (p. 44). Figures for illicit drug misuse also indicate lower prevalence rates (Westermeyer et al., 1988, Gress & Boss, 1996, Christian & Poling, 1997, Pack et al., 1998) (see www.rmhldni.gov.uk for a recent study undertaken by Taggart et al., (2004) that examined the prevalence rates of substance misuse in this population in Northern Ireland).

Impact of Substance Misuse

A small number of papers have described the impact that substance misuse may have on a person with a learning disability. From these papers a number of specific health issues have been identified. These include: increased cardiovascular, respiratory tract, gastrointestinal problems, epileptic activity and violent behaviour; more likely to have a co-morbid mental health problem; have higher levels of risk taking behaviour (including suicide attempts); greater risk of contracting various physical diseases (including sexual and HIV) due to a lack of knowledge; greater levels of being exploited (e.g. physically, psychologically, sexually) and exploiting others; there is a strong link with offending behaviour and greater likelihood of admission into a specialist hospital (Westermeyer et al., 1988, Drake et al., 1993, Clarke & Wilson, 1999, Walkup et al., 1999, Doody et al., 2000, Mayer, 2001, Mc Gillivray & Moore, 2001, ARAC, 2002, Stavrakaki, 2002, Taggart, 2003) (see www.rmhldni.gov.uk regarding recent research undertaken by Taggart et al. (2004) that examined the impact of substance misuse in this population in Northern Ireland).

Risk Factors for Substance Misuse in People with Learning Disabilities

A clearer picture is emerging of the factors that place those individuals with learning disabilities most at risk from abusing alcohol and drugs. These predisposing, precipitating and maintaining factors include: having a high IQ (i.e. borderline to mild learning disability); being young and male; coming from an ethnic minority group; having a specific genetic condition (e.g. FetalAlcohol Syndrome); adolescents with Conduct Disorders, ADHD and Anti-Social Personality Disorders; having a mental health problem (e.g. depression, anxiety, schizophrenia); living in the community with low levels of supervision (Jacobson, 1988, Lindsay et al., 1991, Rimmer et al., 1995, Gress & Boss, 1996, Walkup et al., 1996, Christian & Poling, 1997, Robertson et al., 2000, Drake et al., 1993, Mayer, 2001, Stavrakaki, 2002, Sturmey et al., 2003).

Various social factors also found to predispose, precipitate and maintain people with learning disabilities to misuse alcohol and drugs include: poverty; parental alcohol-related neuropsychiatric disorders; presence of negative role models; neglect/abuse; family dysfunction; deviant peer group; limited educational, recreational and unemployment opportunities; excessive amounts of free time (Jahoda et al., 1988, Cocco & Harper, 2002, Stavrakaki, 2002, Sturmey et al., 2003).

Health Promotion/Education

People with learning disabilities have poorer physical and mental health compared to their non-disabled counterparts (Rimmer et al., 1995, Turner, 1997). From these findings the Department of Health (1995) published 'The Health of the Nation: A strategy for people with learning disabilities'. Within this document there was information about safe drinking patterns and the need for health promotion material highlighting the effects of misuse. However, no mention was given regarding illicit drug use. The development of alcohol and drug literature for this population today continues to receive little attention (Christian & Poling, 1997). Refer to www.rmhldni.gov.uk for a study by Quinn et al., (2004) alcohol and drug education programmes across 60 mainstream and 10 learning disability schools in Northern Ireland.

Assessment, Treatment and Management

Given the co-existing other 'conditions' identified above (i.e. mental health problems, aggression, offending behaviour) that frequently accompany this population, the assessment, treatment and management of such individuals are often fraught with difficulty (Drake et al., 1993, Degenhardt, 2000, ARAC, 2002). A number of studies highlight that people with learning disabilities who misuse substances sometimes can be 'unwilling' or 'un-cooperative' to engage in the treatments offered further complicating the delivery, maintenance and success of such interventions (Rivinius, 1988). Possible explanations for this latter finding centre upon this population's lower level of intellectual ability and associated cognitive deficits compared to their non-disabled counterparts (Degenhardt, 2000, Sturmey et al., 2003). These individuals have also been found to have lower levels of knowledge regarding the effects of taking excessive amounts of alcohol and drugs (this also applies to medications) (McGillivray & Moore, 2001).

Compared to the non-disabled population, Degenhardt (2000) indicated that for people with learning disabilities who misuse alcohol, 'abstinence' may be a more appropriate treatment goal rather than 'controlled drinking'.

'Controlled drinking' involves understanding the rules concerning 'units of alcohol', 'when' and 'where' to drink and what 'not' to drink whereas 'abstinence' only requires the individual to totally restrain from consuming alcohol. Nevertheless, a number of interventions have been offered to people with learning disabilities who have misused alcohol and overall the results appear promising.

These include: detoxification and use of other psychopharmacology treatments (i.e. antabuse); modifications of A.A. & 12 Step Programme; use of group therapy; use of social skills training (e.g. refusal skills, inter-personal communication, expressing emotions, responding to criticism, role playing); motivational interviewing; relapse prevention programmes; behavioural approaches (i.e. assertiveness, daily living skills); and the provision of staff education (Moore & Ford, 1991, Paxton, 1995, McGillicuddy & Blane, 1999, Barnhill, 2000, Stavrakaki, 2002, Sturmey et al., 2003).

Although these studies have been informative, they provide little more than descriptive accounts of either mainstream or modified interventions: with many of these studies found to be methodologically poor (Burgard et al., 2000, Sturmey et al., 2003). Limitations include small sample sizes, lack of reliable and valid measurement tools, studies undertaken within hospitals thereby limiting the person's access to alcohol, lack of control groups, lack of generalisability and no long-term follow-up. Few studies report on the efficiency of the treatment strategies offered.

An expert panel of psychiatrists and psychologists in the USA developed guidelines regarding the 'treatment of psychiatric and behavioural problems' for people with learning disabilities (American Journal on Mental Retardation, May, 2000). These guidelines include:

- education of the client/carer in order to understand and manage the disorder (including communication and social skills);

- managing the environment (i.e. removing environmental provocations, changing activities, work, social groupings, and physical environment); and
- applied behaviour analysis (i.e. learning to build new skills that are functional and appropriate, and reduce problem behaviours).

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Older People - Annexe 10

Treatment Services

The complexity of substance misuse in the older age group can be illustrated by the client/carer relationship e.g. the 'carer' maybe an older person with an alcohol problem who is caring for a spouse with physical or mental health problems.

One of the problems in this area is the lack of systematic evaluation of treatment interventions and an absence of controlled trials (Derry, 2000).

One study found that a sample of 24 older people in out-patient treatment remained in treatment significantly longer and were more likely to complete treatment than a control group treated in mixed groups. (Kofoed et al., 1987) Another study suggested that age specific programmes were unwarranted because although there were statistically significant differences between older and younger problem drinkers there were equally significant differences within the older age group e.g. between late and early onset problem drinkers (Mulford and Fitzgerald, 1992).

Derry has made several recommendations in respect of service provision including age oriented treatment programmes, specialised training packages for staff, outreach services, home detox programmes and clearly defined structures and arrangements for referral to specific medical care i.e. neuropsychological (Derry, 2000).

Risk factors for late onset drinking in older people include female gender, higher socio-economic status and in some but not all studies life stressors, but neither psychiatric co morbidity nor positive family history of alcoholism appears to contribute in a majority of cases (Atkinson, 1994).

It has been suggested that viewing late onset drinking as a response to life stressors may be over simplistic. There may be 2 feedback cycles, a 'harmful' one and also a 'benign' feedback cycle in which, "Problematic drinking and life stressors exacerbate each other, but also a benign feedback cycle in which moderate alcohol consumption and life stressors reduce each other" (Brennan et al., 1999). The aetiology of problem drinking is complex; social, environmental, physical and mental health problems need to be considered. Other factors evident in 2 hospital studies were that alcohol problems might present in a number of non-specific ways e.g. confusional states, gastrointestinal problems, falls and accidents and these may be misdiagnosed or attributed to the ageing process (Niak and Jones., 1994).

There may be a view that advising older people to give up their alcohol habit is inappropriate. There may be perceived difficulties in taking detailed alcohol histories due to physical or mental health problems or cognitive impairment (McInnes and Powell, 1994).

These factors may present difficulties for the practitioner but they are not insurmountable barriers. Problem identification, comprehensive assessments and successful treatment outcomes are all achievable with this client group.

Despite the lack of enthusiasm for taking an alcohol history the outcome of treatment in elderly people who misuse alcohol is good (Niak and Jones, 1994).

It is recommended that a quantative alcohol history should be taken from all elderly people admitted to hospital.

An interesting finding in relation to problem identification and referral to specialist alcohol treatment agencies was that there were higher rates of identification by doctors in hospitals which had on site substance misuse treatment services.

Examples of Good Practice:

1. The Camden and Islington Alcohol Support Association (CASA), older persons service in London has reported on 96 clients using the service during a one year period. 20% stopped their use of alcohol, 52% stabilised or reduced their drinking, and 72% demonstrated some improvement in self care or psychological or social functioning (Taber, 2001). This was a small-scale study and there is a real need for further research in the area of treatment interventions.

2. At present there are 2 age specific treatment services in Northern Ireland. The Northern Ireland Community Addiction Service (NICAS) set up a Service for Older People in 1997 with funding provided by the Community Fund. This provides specialist counselling, and individualised treatment programmes. Domiciliary visits are available to all clients. Other features of the programme are systemic work with families/carers and group work.

   (i) In the 12 month period from April 2003 to March 2004, 102 clients attended in relation to their own alcohol problems. Some outcome evaluation has been carried out but the related research has not yet been completed.

   (ii) Training sessions have been conducted for several statutory and voluntary agencies e.g. awareness raising and interventions.

3. A Domiciliary Outreach Programme was established in the Foyle Health and Social Services Trust in 2003. It is a statutory and voluntary sector partnership and is funded by the Western Drugs and Alcohol Co-ordination Team. It provides counselling, advice and information to clients and carers based on a harm reduction model. Another feature of the service is the support provided to caseworkers in the care planning process.

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People within the Criminal Justice System – Annexe 11

Probation

A senior manager has been designated as responsible for drugs issues (Assistant Chief Officer – ACO). This ACO will represent PBNI on the Drug and Alcohol Strategy Implementation Group.

A Drug Steering Group will be established within PBNI consisting of the Area Managers who sit on Drug and Alcohol Coordination teams, Training Manager, Prison Probation Manager, Youth Justice Manager and a representative from Hostel Forum. The remit of this group will be:

- to improve practice and support practitioners in their work with drug users;
- ensure consistency and equity of service provision and encourage best practice;
- encourage the development of partnership working;
- ensure communication structures are in place to keep employees informed of developments in policy and practice; and
- ensure training needs are met.

The strategy of PBNI includes the following elements:

- accurate assessment of drug using offenders to inform courts of the role played by drug use in offending, the needs of the offender and options for sentencing which will protect the public whilst enhancing the prospect of reducing offending;
- establishing co-operative working relationships with statutory, voluntary and community agencies in delivering services to drug using offenders;
- joint working within multi-agency teams to deliver assessments and supervision where it can be agreed with partner agencies;
- a continuum of treatment and support between custody and community which applies to adults, young offenders and juveniles;
- structured drug awareness and reduction in use programmes as part of supervision and as a condition of an order where appropriate; and
- support families affected by drug misuse, especially those of prisoners and juveniles.

The PBNI in partnership with other agencies have contributed to the following specific projects and working arrangements which have contributed to the assessment and supervision of drug misusers.

(i) Railway Street Addiction Service, Ballymena – in partnership with Homefirst Community Trust.

Their brief is to provide assessments for courts of those offenders referred because illegal drugs, typically heroin use, appears to underpin their offending and to provide continuing treatment as a condition of probation supervision.

Although demand fluctuates, during the first 18 months of operation there were more than 100 requests for assessments and 53 offenders under supervision. The benefits of the project have included:

- the sharing of knowledge and experience within a single team;
- access to the services of respective agencies involved;
- including psychiatric services and hospital detoxification;
- direct referral from court rather than waiting within the referrals from general practitioners; and
- freeing the Community Addictions team from demands of court referrals.

(ii) The Rapid Assessment and Treatment Service for Drug and Alcohol Misusers (RA TSDAM) is a joint initiative between the PBNI and the Northern Ireland Community Addiction Service set up in 2003 (funded by Northern Ireland Office). The purpose of the service is to provide a fast track assessment and treatment service for male and female offenders within the greater Belfast area whose offences are related to their drug use. Referrals come from PBNI. In the first 2 years 230 assessments were completed and a total of 127 Orders were made by the court.

Those accepted for the programme are required to attend 8 weekly cognitive behavioural treatment sessions with further available if needed.

Follow up outcome analysis at 3 and 6 months after treatment indicates encouraging results with a high percentage making meaningful changes. A research component is built into the scheme and high-level analysis is completed for each step of the programme.

(iii) Accredited and Approved Programmes – PBNI support the drive to ensure that work with offenders is of proven effectiveness. Due to a lack of available trainers, it was not possible to adopt the accredited programme, Addressing Substance Related Offending. A local Approval Group has been established, which scrutinises the effectiveness of locally developed programmes.

(iv) Partnerships in Prisons – In the YOC a programme is delivered by Opportunity Youth, a voluntary agency. This programme is continued on release in conjunction with PBNI. Probation staff are also involved in drug programmes in the adult prisons which are continued on release.

(v) Voluntary Agencies – PBNI has working relationships with Dunlewey Substance Advice Centre and Northern Ireland Community Addiction Services allowing for direct referral by probation officers.

Prisons

The current provision of substance misuse services is limited. On committal to a prison establishment, a primary health care assessment is undertaken to identify any prisoner with a history of physical ill-health, mental illness, deliberate self-harm or substance misuse. A general practitioner will engage the prisoner in a detoxification regime.

Following this, a prisoner may receive support from a voluntary agency, Registered Mental Nurse or Consultant in Substance Misuse. Prisoners also receive education regarding drugs and potential risk of overdosing on release. Throughcare is variable, and is dependent on which agency, if any, the prisoner has chosen to engage with. However, the most significant providers of addiction services to NIPS are the voluntary agencies. Services have been commissioned from Opportunity Youth, Dunlewey Substance Advice and Northlands. These projects are evaluated, and there are regular meetings between counselling staff and operational personnel. This gives a significant opportunity for through care on resettlement, and support for families. An example of this is Opportunity Youth, working in Hydebank Wood, who work both with young offenders and their families.

There is a lack of strategic planning and joined up working between prison healthcare staff and the voluntary agencies, as both services run in parallel. There is currently no forum to look at integrated care pathways, to meet individual client's needs. These are discussed in Annexe 11.

NIPS supports a zero tolerance policy regarding substance misuse. This incorporates mandatory drug testing, whereas the Scottish Prison Service has changed to Addiction Prevalence Screening. The Scottish model does not involve any loss of privileges, but rather encourages a prisoner to engage with therapy. Limiting the supply of drugs is a high security priority.

Hepatitis B vaccination is to be made available to all prisoners and staff. Substitute prescribing has commenced following the production of the NIPS Substitute Prescribing Guidelines 2004, without additional resource allocation.

There are other intrinsic difficulties in providing substance misuse services in the prison environment. It is difficult to provide regular sessions with clients, who may be at visits, court, bailed, or locked in their cell. It is difficult to do group work in a secure environment, where prison rules limit prisoners coming together, and most importantly, the effectiveness of many therapeutic interventions have not been evaluated in the prison setting. There is evidence to support Alcoholics Anonymous in the treatment of those with alcohol dependence.

At present the NIPS Drug Strategy is under review. It should consider the following recommendations:

- substance misuse teams should be established to assess prisoners on committal and devise individual care plans;
- substance misuse teams should work in partnership with voluntary agencies, referring prisoners who have completed detoxification;
- substance misuse teams should liaise with resettlement and Community Addiction Teams at time of release; and
- a harm minimisation approach should be adopted including vaccination against hepatitis B, and consideration given to the supply of condoms and needle exchange facilities.

Suicides in Prison CR99 Feb 2002, RCPsych.

- Recommended that all prisons need an enhanced psychiatric and substance misuse service.

- Recommended that community drug teams should have access to prisoners and that all prison doctors should receive specific training in psychiatric and in drug misuse medicine.

- Emphasised that drug withdrawal occurs when prisoners with problems of substance misuse are admitted to prison and this may play a part in generating suicidal behaviour.

- Recommends that prisoners should have access to the same level of healthcare as those outside of prison and that the practice of automatic detoxification of patients stabilised in the community on substitute prescriptions be discontinued. Prisoners and their families should be educated about the loss of tolerance following drug withdrawal programmes.

Changes in Prison Healthcare, RCPsych Substance Misuse Faculty Newsletter, Sept 2004

- In England and Wales, Primary Care Trusts have taken responsibility for commissioning healthcare in prisons.
- There is a high level of self-harm during the first two weeks of incarceration, and this may be due in part to poorly managed detoxification.
- There is a high mortality rate in the first month after release, as people retox themselves again.
- It is envisaged that there will be a greater use of maintenance treatment, based on an Australian study which indicates that maintenance treatment of prisoners reduces hepatitis C conversions and over doses in prison, and is followed by fewer deaths and less re-incarceration after release.
- Recommend forming substance misuse teams, and that these should be led by specialists.

Prison Surveys of Drug Use

- Although there is no published data concerning drug use in Northern Ireland prisons, the total number of drug finds in prisons has shown an increase since the Drugs Policy and Strategy of NIPS was established in 1996.
- A survey in HMP Maghaberry showed that 20% of respondents declared using a Class A drug (heroin, cocaine, ecstasy) within prison in the 4 weeks prior to the survey (2001).
- Previous injecting drug use was reported by 11% of prisoners (cf 43% ROI, 4% UK).
- One fifth of injectors said that they started injecting drugs whilst in prison.
- hepatitis C – 1.06%.
- hepatitis B – 0.76%.
- HIV – 0.

Criminal justice based drug interventions: An integrated approach

A range of different initiatives currently deals with drug misusing offenders as they are processed through the criminal justice system, These include Arrest Referral

Schemes located in police custody suites, Drug Treatment and Testing Orders managed by the probation service and prison based CARAT schemes. In many instances, lack of co-ordination between these services leads to inconsistency of care, inefficient working practices and failure to effectively engage and retain offenders in treatment. This is particularly true of offenders who are released from prison without adequate aftercare arrangements.

The updated drug strategy highlights the aim to join up initiatives in the criminal justice system more effectively and develop an 'end-to-end approach from arrest through to sentence and beyond. Under a new criminal justice intervention programme supported by the Home Office and NTA, 25 Drug and Alcohol Teams covering areas with the highest level of acquisitive crime have been asked to adopt a model of working which would seek to develop a 'virtual or dedicated', community based criminal justice drug team for their area. This approach should where possible build on work and arrangements already in place using a combination of existing and new resources, from the additional capacity building and aftercare funds.

In line with the Models of Care framework, this approach adopts the principle of identifying an integrated care pathway which clearly maps the course of treatment for a drug misuser who is assessed and referred within the criminal justice system (fig 1).

This 'community based team' will accept referrals from police, courts, probation and prisons and their role will extend beyond assessment and referral. There is clear evidence from the arrest referral evaluation (July 2002) that delays between referral and accessing treatment is de-motivating and leads to a high proportion of offenders not engaging in treatment. This learning highlights the need for this community based team to be able to provide and/or access the full range of Tier 2 interventions including case management and low threshold treatment interventions to ensure that offenders are engaged and supported and to maximise the prospects of retaining them in treatment. The new teams will undertake the following tasks:

- triage assessment and referral into appropriate specialist treatment;
- care planning and co-ordination function;
- harm reduction advice and interventions;
- immediate access to low threshold treatment – for instance, structured counselling/motivational interviewing and methadone prescribing;
- appropriate interventions for crack and cocaine users;
- work in partnership with probation and police in contributing to the delivery of DTTO, pre-arrest and prolific offender programmes; and
- provide a dedicated after care service for prisoners being released into the relevant DAT area to address their drug treatment needs and facilitate access to other services like housing, mental health, employment etc. This will include liaising with CARAT teams and probation staff to prepare jointly agreed release plans. Manage a team of volunteer mentors to provide practical support and encouragement for offenders.

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Interface with Mental Health Services – Annexe 12

A Review of Mental Health and Learning Disability (Northern Ireland): A Strategic Framework for Adult Mental Health Services. June 2005 (www.rmhldni.gov.uk).

People with Co-existing Substance Misuse and Mental Health Problems (Dual Diagnosis) (pages 65-68).

Recommendations

(51) Trusts should make provision for people with mental health problems and co-existing alcohol or drug misuse. Local prevalence and needs of people with dual diagnosis should be assessed.

(52) People with co-existing substance misuse and mental health problems should be treated using an integrated treatment model within a single service.

- The needs of those with complex, enduring and relapsing mental disorders can best be met by adult mental health services.
- The needs of those with less severe mental health problems, whose main difficulties are directly related to substance misuse, can best be met by substance misuse services.
- Agreed arrangements need to be established between any specialist services for people with personality disorder and substance misuse services.
- There should be systems of liaison between substance misuse and other mental health services to ensure that people with dual diagnosis have access to the full range of the most appropriate treatment services.
- Physical health problems associated with substance misuse need to be identified and addressed.

(53) The needs of people with co-existing substance misuse and mental health problems in contact with the criminal justice system should be identified and addressed.

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Pregnant Substance Users - Annexe 13

Care of the Person who Misuses Substances During Pregnancy

"Pregnant women with substance misuse problems should receive the same quality of care, respect and dignity as any other pregnant woman throughout their pregnancy. The philosophy and approach to care should ensure that this can be achieved" (Whitaker, 2003)
"Even though we're drug users, we want to be treated with respect"
"Just because I drink does not make me a bad mum. I love my kids"
(Castlemilk, 1998)

The extent of substance misuse in pregnancy in Northern Ireland has been focused primarily on the effects of alcohol use in pregnancy. Hepper (2000) from Queens University identified the impact on alcohol consumption during pregnancy.

Key findings from his report highlight:

1. Alcohol consumption remained high during pregnancy, (60-70%) and relatively unchanged over 4 year period;

2. Behaviour of the foetus is influenced by maternal alcohol reducing its movements and its response to sound;

3. Maternal alcohol consumption during pregnancy influences infant habituation at 5 months gestation;

4. The behavioural effects observed indicate maternal alcohol consumption has influenced, possibly permanently, the functioning of the brain and CNS of the foetus and infant; and

5. These effects are observed at low levels of maternal alcohol consumption (5-6 units per week) and this raises questions regarding the 'safe' level of alcohol during pregnancy.

Studies in Glasgow revealed that in 2000/2001, as many as 4.4 per 1000 maternities, had misused drugs. Acknowledging these statistics, the Scottish Executive issued a document in 2004, Good Practice Guidance for Working with Children and Families affected by Substance Misuse. This guidance reported that the greater the misuse, the greater the risks. It also reported that the more children involved, the greater the need for all professionals to meet the needs of all the family members. The main message underpinned by this document was the need for a comprehensive collaborative approach to care and the need for appropriately trained professionals in the area of substance misuse and family care.

There are prejudices and attitudes in our society that need to be addressed. Klee, Jackson and Lewis (2002) identified that women who abused drugs and alcohol experienced greater social disapproval than men.

Macrory and Crosby (1995) further highlighted that in pregnancy, this was even more evident with the emphasis of care directed toward the unborn child and resulting in many instances of prejudice against the expectant drug misuser.

The negative view of society towards this group of users has resulted in discriminatory practices, which has caused exclusion from care.

Johnston (1998) emphasised the pragmatic approach of harm minimisation as an effective means of caring. He also identified that abstinence can be helpfully thought of as the final goal of harm minimisation. To create this approach to care, which is acceptable and accessible to this group, requires services to be free from negative attitudes and values which would block access to treatment programmes.

The Effective Intervention Unit (2002) identified that most substance-abusing women have substance-abusing partners. This pattern further exacerbates the difficulties, with the influences of male partners impacting on the women's substance misuse. Evidence suggests that if the partner engages in treatment with the woman, the outcomes are better.

The lack of detailed collaborative research to support the extent of harm caused to the unborn child through substance misuse has resulted in women having difficulty in making informed choices to treatment.

Drug Misuse and Dependence- Guidelines on Clinical Management, Department of Health (DOH) (1999) identified the need for substitute prescribing and highlighted 2 key areas: namely opiates and cocaine. For opiates, suitable levels of methadone maintenance and reduction are prescribed for pregnant women. However with cocaine use, the woman is advised to stop immediately as there is no safe drug for substitute prescribing.

A collaborative approach to the pregnant substance misuser will be strengthened through multi-disciplinary training. Training should be seen as an appropriate lever to develop good practice and working between professional groups. Training should, also, underpin the implementation of joint protocols at all levels to guide practice.

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Families – Annexe 14

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Smoking - Annexe 15

Full Recommendations for Smoking and Mental Health – Jeffers 2003

(1) In both hospital and community mental health facilities the smoking status of clients should be ascertained at the time of assessment and monitored thereafter by mental health and primary care services.

(2) All mental health staff should be trained to offer brief advice to clients at a stage when they are likely to be receptive to its import. Such advice might include educational information about the health hazards of smoking, the benefits of cessation with time scales, and smoking cessation supports available.

(3) A staff training programme should be instituted to address staff attitudes to smoking and their own knowledge about smoking and mental health. This training programme will aim to counter the prevailing culture in mental health that smoking is often construed as a necessary or tolerated phenomenon among those with mental health problems. Staff may need training to approach this area with sensitivity and pragmatism.

(4) Specialist staff should be appointed to plan support services for smoking cessation aimed at those with mental health problems, and to implement specialist counselling, group therapies and other supportive interventions (for example, help lines; proactive calling to maintain motivation to quit).

(5) Staff training would also include counselling skills, group leadership skills and a full knowledge of the evidence base related to smoking and cessation methods. It should also include knowledge of the likely barriers to access smoking cessation services for these clients.

(6) Health promotion leaflets and particularly those on smoking, and other cessation materials should be readily available in facilities accessed by people with mental health problems including primary care services.

(7) Nicotine Replacement Therapy (NRT) or other pharmacotherapies should be prescribed as required as part of a cessation programme with specialist support. This is important as there is evidence that some people with mental health disorders continue to smoke in conjunction with taking NRT and so experience distressing effects.

(8) Specialist interventions should aim to enable and empower those with mental health problems to avail of general smoking cessation supportive services. This will facilitate social inclusion. Smoking cessation strategies should be integrated in general rehabilitation that aims to enhance the participation of those with mental health problems in their communities.

(9) Therapeutic groups that apply cognitive and behavioural techniques are indicated to achieve smoking cessation changes. Clients have a preference for methods that have a social orientation. They are likely to derive support from others who experience similar difficulties as themselves.

(10) Psycho-educational interventions within either group or individual counselling contexts are relevant to promote motivation to stop smoking. An assessment can be made of the individual client's stage of thinking about cessation and information appropriate to that stage can be provided.

(11) Group therapy for smoking cessation could pursue parallel goals of promoting more healthy living. Exercise and physical activity are diversions from smoking which improve physical health, self-perception and mental well-being.

(12) Smoke free policies in mental health facilities should aim to mirror smoking prohibitions that exist in the community at large. Where there is a gap a plan should be drawn up that aims to achieve parity and should be time framed.

(13) All health services should be health promoting at all times and should demonstrate health awareness.

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The Wider Environment: Homeless and Employability – Annexe 16

Homelessness and Substance Misuse

Background:

The Information and Research Working Group (created under the Joint Implementation Model of the Drug and Alcohol Strategies) identified the need in 2003 to conduct a province wide needs analysis of individuals who have an alcohol and/or drug problem where homelessness has become a feature. A Steering Group was appointed to oversee a research project exploring this issue, with representation from the Department for Health, Social Services and Public Safety (DHSSPS), the Northern Ireland Housing Executive (NIHE), the Council for the Homeless and the Northern Ireland Community Addiction Service (NICAS). Deloitte was appointed to undertake the research project in conjunction with the Simon Community. The full text can be viewed at www.dhsspsni.gov.uk/publications/2004/submisuse.asp

The overall aim of the research is to provide a detailed account of substance misuse among homeless people that could be used to inform future prevention and treatment activity.

The methodology for the research involved the following activity:

- interviews with 154 homeless people recruited via 33 temporary accommodation providers across Northern Ireland;
- a survey of homelessness and substance misuse service providers; consultation with other stakeholders; and
- a literature review of policy context and good practice in the areas of homelessness and substance misuse.

Policy and Strategy Level Issues:

The issues of homelessness and substance misuse are not well integrated at a policy and strategy level, although there has been some evidence of effective integrated practice at operational level. A number of joint policy and working structures already exist which have a part to play in addressing this issue (for example, PSI Working Group on Homelessness, Homelessness Strategy Partnerships, Supporting People Partnerships and the Model for the Joint Implementation of the Drug and Alcohol Strategies).

However, their current remits, structures and funding mechanisms are not easily mapped in relation to the issue under review. Therefore, a specific bridging mechanism is required to bring various strategies and structures together at a regional level and to identify and meet needs at a local level.

Recommendations

The primary recommendation is that the findings of this research and the issue of substance misuse and homelessness be disseminated widely and that an appropriate co-ordinated response to the problem be developed. The response should span change in both policy and practice including the following:

Policy and Strategy

The research indicates that the interrelationship between the problems of substance misuse and homelessness is sufficiently significant to merit the development of an enhanced strategic structure to deal with the specific issues. Therefore, mechanisms should be put into place to develop a regional strategy for an integrated housing, homelessness and substance use service, both from a preventative and reactive perspective.

A possible model for the strategy is set out overleaf. It suggests a two-tier approach, with a Regional Strategy Group whose role is to set policy and oversee service integration, and 4 Area Groups whose role is to identify and meet local needs. The Area Groups could be sub-groups of the existing DACT s and would feed into the Supporting People Area Partnerships to ensure maximum co-ordination with existing structures and best use of existing funding. It is recommended that if adopted, this model should include statutory and voluntary sector representation from across health, housing and justice/community safety, at a senior strategy level on the regional group and at a senior operational level on the area groups. Suggested representatives are also shown.

In addition to the establishment of this model, reviews of existing strategies should ensure also that the issue of homelessness and substance use is given appropriate weight. For example, any further review of the Regional Drugs and Alcohol Strategy should recommend that specific objectives and actions regarding homelessness and housing are made in the plan, and any further review of NIHE homelessness strategy should include a strategy intent to create an integrated service with health and social service agencies on homelessness and substance use issues.

Proposed Model for Homelessness and Substance Misuse Strategy

Regional Strategy Group

ROLE:
- to develop and oversee a regional approach
to integrated services for homelessness and substance use.

MEMBERSHIP:
Senior level representatives including:
- Regional Drug & Alcohol Strategy Co-ordinator
- Regional Homelessness Strategy Co-ordinator
- Representation (health and housing) from Supporting People Regional Planning Group
- Representative of voluntary sector homelessness providers
- Representatives from Probation, Youth Justice & Community Safety
- Representative of Health Promotion Agency

Northern Area Sub-Group

Southern Area Sub-Group

Eastern Area Sub-Group

Western Area Sub-Group

ROLE:
- to map local services & identify gaps/local needs
- to devise integrated models of service and joint working protocols
- to recommend improvements to current service delivery
- to monitor the implementation of local service changes
- to feed into local structures for Supporting People & Regional
Drug and Alcohol Strategy

MEMBERSHIP
Suggested members in each area are as follows:
- Drug & Alcohol Co-ordination Team Co-ordinator
- Area Homelessness Strategy Co-ordinator
- Chair of Area Supporting People Partnership
- NIHE Area Senior Housing Manager
- Statutory sector treatment provider
- Voluntary sector treatment providers
- Voluntary sector homelessness providers
- Probation, Community Safety & Youth Justice representatives

A Service Continuum

Feedback from homeless people through this research highlights a clear need to ensure that homeless people across Northern Ireland have access to a continuum of integrated services in relation to substance misuse and homelessness. This continuum should be appropriate to different groups with different needs, consistent with the good practice set out in the literature review and the findings of this research, and should include:

- a co-ordinated range of temporary accommodation to meet the needs of current and former substance users and those who have not engaged in substance use, including accommodation to meet the needs of intravenous drug users;
- outreach services for rough sleepers and comprehensive drop-in services ('one-stop shops') that provide non-judgemental information and support to those with more chaotic lifestyles;
- outreach treatment services including harm reduction and other treatment services designed to be more accessible to homeless people;
- detoxification services; and
- better integration between treatment/accommodation services including formal links between NIHE, other homelessness providers and treatment providers on the exchange of information.

An agreed baseline model of service provision should be developed for the region and further analysis should be undertaken to identify needs at an area/board basis. This model may not require significant additional funding resources as the key objective will be to redesign existing services to better meet the needs of the target group.

Information and Prevention Services

This research shows that 2 main groups need health promotion support and preventative services – those in temporary accommodation and those threatened with homelessness due to their substance misuse.

Those in temporary accommodation need support to deal with substance misuse and its impact on both their health and their capacity to move into more permanent accommodation. In particular, the research shows that mental health problems and risk behaviours (including behaviours that put people at risk of blood-borne diseases) should be targeted. The research showed a significant problem with substance use among homeless people but a lack of recognition into its impact on individual's current situation, with low numbers perceiving substance use services as a current need. Therefore, information and prevention services must be designed to be more accessible to those in temporary accommodation, for example, through greater provision of outreach services, clinics in hostels and other on-site support.

Those under threat of homelessness where substance misuse is an issue also need support, and mechanisms should be put in place to ensure early intervention that prevents these individuals from becoming homeless.

The role of primary health care, housing, police and other public services in providing early intervention services should be explored.

The Joint Model for the Implementation of the Drug and Alcohol Strategy and the PSI Working Group on Homelessness have a remit to explore ways in which drug and alcohol harm and homelessness respectively can be prevented.

Training

Feedback from homeless people and providers highlights a training need for those working with homeless people and substance misuse issues. This includes those working in temporary accommodation, frontline housing staff working for NIHE and those working in treatment services. Training needs span awareness raising regarding the needs of those with substance use problems generally, how to identify issues, when to refer people onto other services, appropriate referral points and in-depth specialist assessment.

It is recommended that steps be taken to ensure that those in accommodation services working with homeless people can access a programme of training in substance use issues. The Council for the Homeless offers training in this area for voluntary sector providers but uptake has been poor. If resources can be made available, this offering should be augmented to improve uptake and to ensure that all those providing non-statutory temporary accommodation have access to regular training and support. This should include support to hostels with structuring policies and procedures on drugs and alcohol, offering advice on harm reduction methods and provisions needed and offering advice on Section 8 issues.

As regards NIHE staff, the introduction of the Multi-Disciplinary Assessment Team should meet some of the organisations' needs as regards specialist assessment, but there is also a need for more general awareness raising and training for those coming into contact with homeless people who may have a substance misuse issue.

The training needs of those working in treatment services who may have contact with homeless people should also be considered and a regional programme of training or set of guidelines be delivered.

In developing training, reference should be made to existing guidelines and publications, such as those highlighted in the literature review in Section 5 (e.g. Drugscope guidance for dealing with substance use in temporary accommodation). Guidelines on substitute prescribing that include specific guidance in relation to working with homeless individuals with opiate dependency should also be disseminated.

Employability

Employability is defined as: "…. the capability to move into and within labour markets and to realise potential through sustainable and accessible employment.

For the individual, employability depends on:

1. The knowledge and skills they possess, and their attitudes;

2. The way personal attributes are presented in the labour market;

3. The environmental and social context within which work is sought; and

4. The economic context within which work is sought".

(Northern Ireland Task Force on Employability and Long Term Unemployment, 2002). Moving On Update: Education, Training and Employment for Recovering Drug Users (Early Interventions Unit, Scotland, 2003) expands this definition to focus on the individual's unique resources, i.e. the attributes and assets, and ability and capability to use those attributes and assets.

The review supports the suggestion of better joined up working between agencies already providing employability and rehabilitation services;

- Disablement Employment Advisors,
- Job Brokers,
- Occupational Therapists,
- NIACRO,
- Northern Ireland Union of Supported Employment,
- Action Mental Health,
- Department of Employment and Learning,
- Voluntary providers (Dunlewey Substance Advice Centre, Ballymena
- Family and Addicts Support Group, Northern Ireland Community Addictions Service, etc),
- Institutes of Further and Higher Education,
- Volunteer Bureaus,

- Educational Guidance Service for Adults, and
- Employers, etc.

It is acknowledged that a wide range of underlying issues and barriers must be addressed for many people in this target group. These include; mental health or general health problems, poor essential skills, lack of workplace skills, personal and emotional issues including lack of confidence, lack of motivation and negative family or peer pressure or a worklessness ethic. Obtaining and maintaining employment will be challenging for some of the individuals concerned.

The Eastern Drug and Alcohol Coordination Team (EDACT) and the Department of Employment and Learning (DEL) organised a seminar on the issue of employability as an essential factor aiding a person's recovery from substance misuse.

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The BAMFORD REVIEW of MENTAL HEALTH and LEARNING DISABILITY (Northern Ireland)

AUTISTIC SPECTRUM DISORDERS

Background

1. From its outset, the Bamford Review of Mental Health and Learning Disability (NI) has been conscious that people with an Autistic Spectrum Disorder (ASD) have a wide variety of needs, some of which are currently being met within learning disability services, some within mental health services, some within other programmes and some needs are not being met at all. By way of illustration, in Priorities for Action 2003/2004 autism is referenced in three separate service areas - mental health, learning disability and child health.

2. The Review has given serious consideration to how the needs of people with ASD should be met. At the core of the Review's deliberations has been determining how the range of effects of autism can best be addressed and the consequent diversity of required interventions developed within the two components of the Review i.e. mental health and learning disability.

3. Reports from individual Review Committees are addressing the needs of people with ASD within their respective remits. For example, the Adult Mental Health Expert Working Committee report includes a section on 'Services for People with Asperger's Syndrome or High Functioning Autism' with related recommendations. The 'Equal Lives' document on Learning Disability also makes reference to the complex needs of those with both a learning disability and autism. However, it was concluded that the needs of all those with an ASD and their carers should be the subject of a separate and overarching paper by the Review.

4. In compiling the following framework for the future development of comprehensive autism specific services, it was acknowledged that excellent and expert guidance has been issued in recent years. The Review gave due consideration to several national and regional documents, as listed at Annex A.

5. To inform the Review's work on ASD, a major stakeholder event was held in December 2004 to establish priority needs for service development in Northern Ireland. Workshops considered the needs of children and adults who have autism, those with a learning disability and those who do not have an intellectual impairment, compiling an agreed list of priorities. Common and recurrent themes that emerged from each workshop form the basis of this policy framework for the future development of autism specific services.

6. The Review has deliberately provided broad recommendations for future service development, recognising that Health and Social Services Boards and Trusts are at different stages in current provision. However, the key recommendation of the

Review is that a senior manager in each Trust should be given responsibility for the development of autism specific services and the co-ordination of these across programmes of care. Service provision for ASD must embrace partnership approaches that integrate and provide a whole systems approach, so collaboration with other relevant agencies such as education authorities will be an important component of the manager's role. Those identified as having responsibility for ASD should consult respected documentation that has been published previously if more detail is required. A needs assessment of people with ASD and their families should be completed as a priority.

New funding must be prioritised to underpin the Review's recommendations on ASD services.

Key Areas for Service Development

1. Assessment and Diagnosis

Timely and accurate assessment and diagnosis is a vital first step in meeting the needs of people with ASD and minimising the adverse effects of the condition. Delay in diagnosis is often attributable to poor co-ordination and fragmentation of services. There is increasing evidence that diagnosis is more accurate and can be achieved at an earlier age (ideally around 2-3 years) where assessment is multi-disciplinary and ASD specific. Evidence-based models of practice advocate an intensive diagnostic approach with both child and family in attendance with assessment being undertaken by a range of specific practitioners from relevant agencies.

While much of the work should be concentrated on early assessment in young children, the assessment needs of older children and adults must not be ignored. Knowledge of the size of the challenge in adulthood (its epidemiology, the number and kinds of services that would be needed) is poor, but likely to improve rapidly over the coming years. Expertise in relation to adults with Asperger's Syndrome/High Functioning Autism is lacking and needs to be developed.

Recommendations

- Autism specific diagnostic and assessment services must be established in each Trust.
- Providers should offer ASD specific diagnostic and assessment services for children and adults, regardless of intellectual ability.
- Professionals involved in this work must be highly trained, skilled and experienced in child development and in relevant disorders including mental health problems.
- Expertise in relation to adults with Asperger's Syndrome/High Functioning Autism needs to be developed.
- Child and Adolescent Mental Health professionals must acquire greater knowledge and experience in assessment and diagnosis of ASD.
- There should be a clear pathway to diagnostic and assessment services for families once ASD is suspected.
- Quality standards for the process of assessment and diagnosis are required to ensure consistent good practice.

2. Intervention

Diagnosis should act as the stimulus for provision of a range of appropriate interventions in response to the assessed needs of people with ASD and their families. As with assessment, a co-ordinated approach and multi-disciplinary working are essential.

Recommendations

- All children and adults receiving a diagnosis of ASD must be offered appropriate and timely intervention based on best available evidence.
- These must be person-centred, delivered by adequately trained practitioners and provided on an inter-agency basis, as appropriate.
- A ‘keyworker’ model should be developed for each individual with ASD and their family/carers, to ensure access to autism specific services and any other services that may be required.
- There must be a clear referral pathway to appropriate mainstream services that may be required by a child or adult with ASD.
- For some, specialist medical care and intervention will be required as appropriate. People with autism should receive this from medical practitioners trained in an understanding of autism.
- A wide range of interventions will be required to meet the spectrum of needs presented by children and adults with autism.
- Those responsible for service commissioning and delivery will need to keep abreast of current developments, research and efficacy of interventions for autism.

3. Individual and Family Support

Services must be person-centred and recognise the importance of work, leisure and social activities to the person’s health and wellbeing. There is a need for forward planning and good co-operation between services at key transition stages of life.

Service providers must also recognise the valuable contribution being made by families and other carers and seek to provide information and support to them in their role. Respite services, which may range from youth clubs, play and befriending schemes to family based or residential breaks, are central to supporting families.

Recommendations

- Emotional and practical support for the individual and their family must follow confirmation of diagnosis in a timely fashion.
- Particular attention must be given to supporting the individual and their family during ‘transition’ times. For example, primary to secondary school, leaving school, moving away from the parental home.
- Careful planning will be needed particularly for transition between child and adult services to ensure continuation of the support required in adulthood.
- Respite services require to be developed by specialist, mainstream and voluntary sector services as appropriate.
- Respite should be planned in advance and not reactive to family crises.
- All children and adults with autism should have access to leisure and meaningful activity tailored to their needs and interests that promotes social inclusion.
- Support is required for children to develop their social skills and understanding.
- Adults should be able to access social groups developed with their participation and tailored to their needs and interests. These will aim to help them learn how to form relationships, develop community and social skills.
- Adults with autism who wish to receive further and higher education should be supported to do so through the provision of educational and support services. These must reflect the needs of students with autism through person-centred assessment.
- Assistance for adults in finding an appropriate job, with access to autism-specific employment advice and support needs to be developed in their local area. (The Disability Discrimination Act now requires that employers make ‘reasonable adjustments’ to reduce and remove any substantial disadvantage to a disabled employee or job applicant.)
- A range of supported accommodation options to meet the needs of current and future adults in their area must be developed.
- The model of ‘care planning’ and ‘care management’ should be adopted to support the individual with ASD and their family or carers.

4. Training

Staff delivering services to people with ASD and their families must be adequately trained to ensure they are competent for the task. In addition, families and carers need training to fulfil their role. Better general awareness of ASD among primary care and community staff, especially those dealing with young children, would enhance recognition of problems and facilitate earlier referral for assessment.

Recommendations

- A regional training strategy for parents and staff must be developed.
- Two tiers of training are necessary – awareness and specialist training.
- An awareness training programme should be available to all staff in contact with children or adults with ASD who require a basic understanding of the condition.
- Basic awareness training at pre-qualification level for professionals likely to come into contact with people who have an ASD should become standard practice.
- Specialist training is essential for those involved in diagnostic assessment of ASD and/or intervention for individuals with ASD and their families or carers.
- Training should be delivered by professionals who are ‘accredited’ or have recognised expertise in ASD to ensure quality is maintained.

5. Management and Co-ordination of ASD Services

The Review wishes to see an integrated service for people with ASD which builds on existing services to provide a more comprehensive and coherent response to need. Strategic direction for such service development is essential and the Review, therefore, recommends that a senior manager should be identified in each provider unit to assume overall responsibility for ASD services for both children and adults. Service development plans should be informed by robust needs assessment.

Recommendations

- A senior manager in each provider unit should have overall responsibility for the development and coordination of services for children and adults with ASD.
- He/she will ensure the development of autism specific services within existing programmes of care - community, mental health, learning disability and children’s services, including child and adolescent mental health.
- It will be his/her responsibility to set up a co-ordinating group for strategic planning, audit and evaluation of ASD services.
- A major role will be to involve and co-ordinate relevant statutory and voluntary agencies in provision of services for people with ASD and their families or carers.
- Each provider should develop adequate information systems to assess need and inform future planning services at local and regional level.

6. Responsibility for ASD Services

The needs of people with ASD are varied and current service responses span several programmes of care. This can result in lack of co-ordination of services and poor impetus for service development. The Review considers that the creation of a separate programme of care would, among other things, divert scarce and much needed resources from the development of direct service provision for those affected by ASD and could lead to further marginalisation of people with ASD. However, it is imperative that the existing programmes of care structure do not impede future development of, or access to, autism specific services.

Implementation of the Review's recommendations depends on robust commissioning services, both regionally and at local level.

While much of the emphasis for assessment will properly focus on children and younger people, the life-long nature of the condition means that the need for services will continue into adulthood.

Recommendations

- Commissioners of services must ensure that providers specify organisational responsibility for implementation of ASD services across all programmes of care.
- The Review recommends that the Learning Disability Programme should be responsible for service development for those with ASD and learning disability; the Children's Services Programme for children and young people with ASD; and the Mental Health Services Programme for adults with ASD.

Annex A

Relevant national and regional documents on ASD

Taking Responsibility
Good practice guidelines for services – adults with Asperger Syndrome.
National Autistic Society, 2002.

The National Autism Plan for Children.
National Initiative for Autism: Screening and Assessment (NIASA), 2003.

All Party Parliamentary Group on Autism (APPGA), Manifesto Principles.
National Autistic Society, 2003.

Report of the Task Group on Autism.
Department of Education for Northern Ireland, 2002.

Priorities For Action 2003/2004.
DHSSPS, 2003.

Development of ASD Services: Diagnosis & Early Intervention.
Four (H & SS) Board Paper, 2004.

THE BAMFORD REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY
(NORTHERN IRELAND)

MENTAL HEALTH IMPROVEMENT AND WELL-BEING - A PERSONAL, PUBLIC & POLITICAL ISSUE

May 2006

MENTAL HEALTH IMPROVEMENT AND WELL-BEING – A PERSONAL, PUBLIC AND POLITICAL ISSUE

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FOREWORD

Mental health is as important as physical health. Mental health promotion, therefore, is not just for those with mental health problems. Mental well-being underpins all health and well-being: it is a resource which must be protected and promoted. For these reasons, the Review established a specific Expert Working Committee on Mental Health Promotion. Like all of the Committees it adopted an evidence-based approach, drawing on existing relevant information and research and examples of best practice, locally, nationally and internationally.

Mental health promotion is also central to achieving the Review's vision and principles for the reform and modernisation of mental health and learning disability services. The subject matter of this Report, therefore, overlaps with and impinges upon most of the Review's other Working Committees, and is an underlying principle of all our reports.

The task for Government is to address these challenges and the recommendations necessary to realise them.

I thank Professor Alan Ferguson and his Committee for their work in producing this Report, which I commend to you.

This is the first report of the Review since the passing of our Chairman, Professor David Bamford. We have lost a true friend and inspirational leader. The Review owes him a great debt and it is our hope that the reports and their subsequent impact on service reform will be a fitting tribute to his life and work. In recognition of David's contribution to our work, the Minister, Shaun Woodward, has agreed to our request that the Review will now be recognised as the Bamford Review of Mental Health and Learning Disability (Northern Ireland).

Roy J McClelland (Professor)
Chairman

MENTAL HEALTH PROMOTION

Executive Summary

1. THE CHALLENGE

Mental well-being and improvement is a personal, public and political matter. Mental health promotion is concerned with how individuals, families, organisations and communities think and feel.

Over 19% of the total burden of disease in Western European countries was attributable to mental illness compared with 17% for cardiovascular disease and 16% for cancer. In 2002 no other condition exceeded 8% (World Health Organisation, WHO 2004).

Of the total disease burden in Western Europe, just over half is attributable to non-fatal outcomes of morbidity and disability, of which mental ill health accounts for over 30%. No other health condition accounts for more than 10%. In Northern Ireland we are only spending approximately 9.3% of our Health and Social Services Budget on mental health.

The 2001 Northern Ireland Health and Well-Being Survey found that 21% of our population aged over 16 considers themselves to be depressed and a similar percentage had a potential psychiatric disorder. The Department of Health, Social Services and Public Safety (DHSSPS) estimate that in terms of the scale of the problem, prevalence figures for mental health problems in Northern Ireland are 25% higher than in England.

Addressing these challenges for the whole community in Northern Ireland, as exemplified by the WHO Action Plan for Europe (WHO 2005), is a long-term investment. That investment must reflect the growing body of evidence that positive mental health cannot be gained by treating mental disorders alone.

2. VISION AND PRINCIPLES

The Review has considered how best to promote positive mental health for the whole community and the impact of the Promoting Mental Health - Strategy and Action Plan 2003-08 (DHSSPS 2003). It also considered how best to meet the needs of people at risk of suicide.

The following vision is central to the success of a mental health improvement strategy.

There must be a recognition at all levels in Northern Ireland that:

- everyone has mental health needs;
- mental well-being underpins all aspects of health and well-being; and
- mental health, like physical health, is a resource to be promoted and protected.

The Vision must be underpinned by the following principles.

To achieve a society where everyone plays a role in and takes action to create an environment that promotes the mental well-being and improvement of individuals, families, organisations and communities, there is a need for:

- increased cross-sectoral, collaborative work among key agencies and central government departments – partnerships between health and social services and education agencies hold particular potential;

- mental health to be promoted in the context of social justice, equality and citizenship;

- socio-economic and environmental factors to be highlighted - deprivation increases risk of mental health problems across the spectrum of disorders, and fragmented environments are risk factors for depression and suicide;

- mental health promotion to take place with the whole community , individuals at risk, vulnerable groups and in key settings - long-term strategies need to look at the bigger picture and see how the different dimensions can be integrated; and

- understanding that poor mental health is not a random misfortune but is strongly associated with unemployment, less education, low income or material standard of living, in addition to poor physical health and adverse life events.

These values and principles are especially important in Northern Ireland, where social capital has in many communities been greatly diminished by 30 years of conflict. Communities need to grow and develop, enhance their levels of trust and sense of belonging and participation in order to promote emotional well-being.

Although some progress has been made towards this vision, much remains to be achieved.

3. PRIORITIES FOR PROMOTING MENTAL HEALTH IN NORTHERN IRELAND

In reviewing progress on mental health promotion in Northern Ireland, the following areas have emerged as crucial to achieving effective delivery:

- cross-sector partnership and working;

- co-ordination;

- dedicated resources, both additional and with a realignment or reconfiguration of existing resources to facilitate mental health promotion and prevention;

- compliance with equality and human rights legislation;

- capacity building;

- prioritisation of key risk groups; and
- research.

4. RECOMMENDATIONS

To realise the vision for mental health promotion there is a need for a focused, resourced, centrally driven, cross-sectoral, cross-departmental and prioritised approach.

Primary Recommendation – The Creation of a Regional Mental Health Promotion Directorate at the Heart of Government

In order to achieve these objectives, the Review is recommending the establishment of a Regional Mental Health Promotion Directorate with a Regional Director.

The Review, having agreed and recommended a Directorate as necessary for providing strategic, co-ordinated, cross-sectoral and multi-agency action on mental health promotion, then considered the appropriate structures and siting to achieve this function.

The Review considered where the centre of gravity should be for this recommendation. Should it be focused within the health sphere or if we are looking to wider contributions, including those of education, culture and employment to produce the change we want, what mechanism and approach is most effective in making those linkages?

The Review considers that it is necessary, in order to achieve this strategic vision, to place the Mental Health Promotion Directorate at the heart of Government. The Review's recommendation is that to ensure mental health promotion is a policy priority across the whole of the public sector the Directorate would best be placed within the Office of the First Minister and Deputy First Minister (OFMDFM).

The assigning of the Directorate to a single Department or Quango should be avoided to ensure that ownership of mental health promotion is not perceived as being the sole responsibility of a single Department, such as Health and Social Services. The assigning of a Directorate for Mental Health Promotion to OFMDFM fits in well with the portfolio of responsibilities already assumed by this Department. These include such issues as equality, children and young people, disability, human rights, as well as the Department's responsibility for promoting co-operation between Government Departments in Northern Ireland.

Key Functions of the Directorate

A properly resourced Directorate would increase awareness and visibility of mental health promotion, facilitate the achievement of existing mental health promotion targets as well as setting targets for the future. This would provide a necessary degree of permanence, leadership and the sustainability to drive forward mental health promotion in Northern Ireland, whilst creating ownership of mental health promotion across all sectors and relevant agencies and groups.

A Mental Health Promotion Directorate sitting within the heart of Government, would ensure that mental health promotion contributes to the goals and policies across all sectors, supports the delivery of existing policies relevant to mental health promotion, raises the awareness of mental health promotion and moves mental health promotion up the policy agenda in all Government Departments and agencies. The Directorate would be responsible for ensuring that the HSS Authority and the new Education Authority take on the responsibility for operationalising the impact of this policy in these 2 important sectors.

Other Recommendations

The Report recommends that for the initial strategic period the settings, stages and levels of action approach to mental health promotion, as outlined in Chapter 5, would be the firm basis for action. Recommendations to achieve this are set out in Chapter 7.

Recommendation 1:	Settings, stages and levels for action:
• Settings for Action	schools, primary care, workplace, further and higher education, communities, including marginalized groups and faith communities;
• Stages of Life	children and adolescents, older people, people in receipt of statutory mental health services;
• Levels of Action	regional level/building capacity.
Recommendation 2:	Deals with the identification of resources and recommends a resource allocation in the region of £5-6 million over the initial 3 year period.
Recommendation 3:	Suicide prevention is an integral part of mental health promotion and the recommendation is that suicide prevention needs to be placed as a public health priority and a Regional Mental Health Promotion Directorate needs to ensure that a separate suicide prevention strategy is implemented as part of its overall responsibility.

CHAPTER 1

INTRODUCTION

Context

1.1 This Report outlines the findings and recommendations of the Mental Health Promotion Expert Working Committee, one of 10 Expert Working Committees established to take forward key aspects of the independent Review commissioned by the Department of Health, Social Services and Public Safety (DHSSPS) of policy, practice and legislation relating to mental health and learning disability.

1.2 The fact that a specific expert working committee on mental health promotion has been established as part of the overall Bamford Review of Mental Health and Learning Disability in Northern Ireland has ensured that mental health promotion will be seen as being an important, indeed underpinning dimension of the Review, and will increase the sense of commitment to the promotion of mental health regionally.

The Aims of the Mental Health Promotion Expert Working Committee

1.3 The Terms of Reference for the Committee were to consider how best to promote positive mental health in society, with particular reference to the impact of the Promoting Mental Health Strategy and Action Plan 2003-08 (DHSSPS 2003), and how best to meet the needs of people at risk of suicide.

1.4 The Committee did not consider its remit was to draft an alternative strategy to the Strategy and Action Plan 2003-08, however, it did consider it important to comment on its implementation to date, seeking views from key stakeholders. Neither does this document attempt to be a comprehensive account of mental health promotion per se or to map all existing practice in Northern Ireland in this field. Rather, it is intended to offer a vision for the future of mental health promotion in Northern Ireland, providing examples of evidence-based good practice, and most importantly, a recommendation on the key issue of where the responsibility for mental health promotion should lie.

1.5 Although the remit of the Committee included the task of exploring the needs of those at risk of suicide, this report does not include a suicide prevention strategy. This has been addressed in a separate Government Report, “Protect Life, A Shared Vision, The Northern Ireland Suicide Prevention Strategy and Action Plan 2006 - 2011”. However, one major recommendation relates to the prevention of suicide (Annex 2 outlines key recommendations on suicide prevention - McGale & McGreevy 2005).

1.6 Therefore, the Committee set out to:

- analyse the current situation in Northern Ireland in terms of mental health promotion, including a commentary on the current strategy;

- identify gaps in provision;
- explore examples of good practice regionally , nationally and internationally , looking broadly from policy issues through to interventions and considering how they might translate to the Northern Ireland context;
- comment on the relationship of mental health promotion to some of the issues addressed by other working committees; and
- provide a vision for the future, highlighting innovative thinking in the area of mental health promotion and prevention.

CHAPTER 2

VISION AND PRINCIPLES

Vision – Mental Health for All

2.1 Mental health is a matter of universal concern; the importance of mental health is gaining growing recognition within Northern Ireland, in the UK and across Europe. The World Health Organisation, at the European Ministerial Conference on Mental Health, Helsinki (12-15 January 2005), produced a "Mental Health Action Plan for Europe, Facing the Challenges, Building Solutions".

2.2 This WHO Action Plan (2005) proposes ways and means of developing, implementing and reinforcing comprehensive mental health policies in the countries in the World Health Organisation (WHO) European Region, requiring action in 12 areas (for more information Chapter 6 and Annex 4).

2.3 We want to see a recognition at all levels in Northern Ireland that everyone has mental health needs; that mental well-being underpins all health and well-being; that mental health, like physical health, is a resource to be protected and promoted. We also want to see a society where everyone plays a role in/takes action to create an environment that promotes the mental health and well-being of individuals, families and communities.

Principles

2.4

- Mental health underpins all aspects of our health and social well-being and, therefore, should be seen as an integral part of all health and well-being services provision.
- There is a need for increased cross-sectoral collaborative work with other key agencies and central Government departments - partnerships between health and social services and education agencies hold particular potential.
- Mental health needs to be promoted in the context of social justice, equality and citizenship.
- Socio-economic and environmental factors need to be highlighted; deprivation increases risk of mental health problems across the spectrum of disorders, and fragmented environments are risk factors for depression and suicide.
- Mental health promotion is relevant to all life stages - from birth to old age.
- Mental health promotion can take place with whole populations, individuals at risk, vulnerable groups and in key settings - long-term strategies need to look at the bigger picture and see how the different dimensions can be integrated.
- There should be flexibility in terms of the use of language; there may be a need for different terms and language for different audiences.

- The increasing amount of evidence-based research into effective mental health promotion needs to be drawn upon.
- A strategic approach to mental health needs to include action to improve treatment, services and quality of life for people living with enduring mental illness, to tackle stigma and discrimination, and to promote mental health for the whole population.

CHAPTER 3

THE ACTION

Prevalence of Mental Health Problems

3.1 Mental health promotion is a personal, public and political matter Mental health promotion is concerned with how individuals, families, organisations and communities think and feel. Drawn from a growing body of evidence it is obvious that mental well-being influences, and is influenced by, health and social outcomes across a wide range of domains, including health behaviours, educational achievement, employment, physical health and crime. The need for a cross-sectoral approach to mental health promotion cannot be over emphasised, particularly the fact that it is not solely a matter for the health service.

3.2 Essentially the case for mental health promotion and prevention starts from the fact that, whatever the metric, mental illness imposes an enormous burden on society. There are three main reasons:

- **Firstly**, mental health problems have very high rates of prevalence.
- **Secondly**, the problems are often of long duration, even lifelong in some cases.
- **Thirdly**, both because of their intrinsic nature and because of additional factors such as stigma and discrimination, mental health problems have extremely widespread repercussions, with adverse impacts on many areas of individuals' lives including education, employment, income, housing, personal relationships and social participation.

3.3 Many initiatives on mental health promotion are happening at local level and the hard work and commitment of individuals and groups must be acknowledged, as well as the potential of the current Strategy and Action Plan 03-08. However, a single Department approach has not delivered on a focused outcome. What we still lack is an effective, focused regional structure, properly resourced, sustainable and able to drive forward and build on existing policy. Such a structure is necessary to achieve in effect mental health promotion outcomes in the broader public health arena for all the citizens of Northern Ireland within an acceptable timeframe. It is also necessary to ensure that a much wider range of agencies, sectors and settings play a part in promoting mental health: mental health promotion needs to feature on the agenda for those involved in education, employment and the workplace; housing, criminal justice, culture and the arts; sports and leisure and local Government.

Key Domains for Mental Health Promotion

3.4 The Review has identified three key domains for the promotion of mental health which inform the approach of this Report and its recommendations.

3.5 **Promotion of Mental Health and Well-Being for All in the Population at Large** - mental health promotion can promote mental health and well-being for all, particularly through a healthy settings approach. The workplace is one example of an arena with much potential for promoting good mental health by providing a supportive culture and reducing undue stress. Employers, however , are often reluctant to address the often complex and subtle issues relating to mental health.

3.6 **The Prevention of Mental Health Problems in Key at Risk Groups** - the Review has identified some key groups as being particularly at risk. These include:

- children and adolescents;
- people who are deaf or hard of hearing;
- people with a learning disability;
- ethnic minorities;
- older people;
- people affected by unemployed;
- people with a physical illness;
- people with gender and sexuality issues;
- people traumatised by sexual abuse; and
- people within the criminal justice system.

3.7 **Improving the Quality of Life for People Who Have Experienced Mental Health Problems** - mental health promotion can improve the quality of life of people with mental health needs. Stigma has long been particularly associated with this group as a problem and can be difficult to address in terms of changing attitudes. Assessing to what extent various agencies comply with the relevant equality legislation can be one approach.

Groups include:

- people with enduring mental illness;
- people with eating disorders;
- people at risk of suicide;
- people emotionally and physically traumatised due to the NI “T roubles”; and
- people involved in substance abuse/dual diagnosis.

Northern Ireland

3.8 The 2001 Health and Well-Being Survey indicated that 21% of the population aged over 16 in Northern Ireland consider themselves to be depressed and that a similar percentage had a potential psychiatric disorder . Women were one and a half times more likely than men to report having suffered from mental health problems. Such rates are over 20% higher than in England and Scotland. People who said they have been affected a lot by the Troubles were almost twice as likely to show signs of a possible mental health problem (34%) as those who had not been affected much (18%).

3.9 The 2002 Health and Lifestyle Survey conducted by the Health Promotion Agency (HPA) found that a quarter of respondents (23% of men and 26% of women) showed signs of a possible mental health problem by scoring highly on a General Health Questionnaire. Those with no qualifications and those on a low weekly household income were more likely to show signs of a possible mental health problem. Depression and anxiety were greatest in the 35-54 and 55-69 year age groups (HPA 2005).

3.10 In terms of the scale of the problem, prevalence figures for mental health problems in Northern Ireland are 25% higher than in England (Effectiveness Evaluation: Health and Social Care, DHSSPS 2003, Chapter 7).

3.11 The high prevalence of mental ill health is compounded by our particular risk factors, including the effects on mental health of economic and social deprivation, unemployment and recovery from the trauma of the Troubles.

3.12 Suicide trends over the last 10 years show a 27% increase in Northern Ireland, (and a similar increase in the Republic[1]) compared to a 9% decrease in the UK overall (http://www.nisra.gov.uk).

3.13 **Figures from a range of UK studies suggest that:**

- At any one time, one adult in 6 has a mental health problem, commonly anxiety, depression, phobias, obsessive compulsive and panic disorders. Around half of people with common mental health problems are limited by their condition and one fifth are disabled by it (Melzer et al 2004). In the past year, one in 200 adults had a psychotic disorder and one in 25 a personality disorder, (Singleton et al 2001; Meltzer et al 1996). GPs spend one third of their time on mental health issues.

- 10% of children aged 5 to 15 experience a clinically defined mental health problem and the prevalence of problems has been increasing over the past 50 years. These include anxiety disorders (4%), conduct disorders (5%) and hyperactivity (1%). Autistic disorders, tics and eating disorders were attributed to half a percent of the sampled population. Prevalence of mental health problems is greater among boys than girls: 11% compared with 8%. Rates of depression and anxiety among teenagers have increased by 70% in the past 25 years (Collishaw et al 2004).

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[1] Data for the Republic of Ireland refers only to deaths recorded as suicide and is therefore not accurately comparable with data from England, Scotland, Wales and Northern Ireland.

- Gender has a significant impact on risk and protective factors for mental health. Rates of suicide are four times as high in men as in women (with the exception of young Asian women) and the difference is increasing (Meltzer et al 1996). However, women are at greatly increased risk of depression and anxiety, eating disorders and self-harm (Piccinelli & Wilkinson 2000, Department of Health 2002).

- Among older people, 10-15% of people over 65 have depression and 3-5% severe depression. Poor levels of mental well-being in older people are both a cause and a consequence of social isolation and also impact on health outcomes for chronic diseases (Godfrey & Denby 2004).

Risk Factors Impacting on Mental Health

3.14 Northern Ireland faces a particular challenge given its particular legacy of the conflict over the past 30 years.

3.15 As the Strategic Framework for Adult Mental Health Services points out in terms of impact of 30 years of civil conflict:

> *"In a random sample of 1,000 adults, Cairns et al found 16% to be "direct" victims and 30% "indirect" victims of civil conflict. Perceptions of being a victim were consistently associated with poorer psychological well-being".*

3.16 Whilst socio economic and environmental factors have greatly improved, and paramilitary activity has reduced over the past decade or so, there are still in many sectors of society thinly veiled underlying threats of violence and intimidation.

3.17 There is still much work to be done societally, to help improve a sense of social cohesion, trust, safety and sense of participation – all key elements of social capital and emotional well-being.

3.18 Both bullying and being bullied are associated with outcomes with a high social and economic cost: criminal behaviour and alcohol abuse (bullies), and depression and suicidal behaviour (victims of bullying). In a school setting, anti-bullying schemes which involve the whole school, parents and the community, eg the Campaign against Bully-Victim Problems, are effective. Follow-up found a 50% reduction in bully/victim problems for boys and girls across all grades with more marked effects after 2 years. There were also significant reductions in anti-social behaviour such as vandalism, fighting, truancy, theft and drunkenness **and significant** long term impacts on criminal behaviour, alcohol abuse, depression and suicidal behaviour (Olweus 1993; 1995).

The Cost of Mental Health Problems

3.19 It is difficult to assess the costs of promoting mental health across Northern Ireland's society through all Government departments and agencies, through schools and through workplaces. However, the cost of not promoting mental health is beginning to be quantified (Mental Health Foundation 2005). The total cost of mental illness in Northern Ireland (2002-03) was £2,852 million (Counting the Cost NIAMH, Sainsbury 2003).

3.20 In both England and Northern Ireland the aggregate costs of mental illness are more than the total amount of public spending on health and social care for all health conditions combined. For example, the estimate of £2.8 billion for the costs of mental illness in Northern Ireland compares with a total HPSS budget in 2002/03 of £2.4 billion. In another comparison (available for England only), it was found that the costs of mental illness appear to be greater than the total costs of crime.

3.21 The share of (HPSS) budget spent on mental health in England is 11.8% compared to 9.3% in Northern Ireland (NI Department of Finance and Personnel 2002 Executive Budget and Public Expenditure Plans).

3.22 To match the English share, spending on mental health in Northern Ireland needs to increase by 26% or £60 million (Counting the Cost NIAMH, Sainsbury 2003).

3.23 It is worthy of note that the share of mental illness in total NHS spending is significantly lower than its share of the overall burden of disease as measured by the WHO and very much lower than its share of total morbidity and disability.

The Global Burden

3.24 WHO work on the global burden of disease using a composite non-monetary measure, the Disability-Adjusted Life Year (DALY), to combine morbidity and premature mortality in a single figure. Estimates for Western European countries, including the UK, show that mental illness now accounts for more DALYs lost per year than any other health condition. Thus the figures for 2002 indicate that 19.3% of the total burden of disease was attributable to mental illness (including suicide), compared with 17.1% for cardiovascular disease and 16.5% for cancer. No other condition exceeded 8% (WHO 2002 statistics www.who.int/healthinfo/statistics/gbdwhosubregionaldaly2002.xls).

3.25 WHO work also includes an analysis of the overall burden of disease by major risk factor. This shows, for example, that in the Western European countries as a group 12.2% of total DALYs lost per year are associated with smoking, 6.7% with alcohol misuse, 6.4% with raised cholesterol and 5.4% with obesity and overweight. According to these figures, the costs of mental illness are thus greater than those of smoking and drinking combined.

3.26 Of the total disease burden in Western Europe, just under half is attributable to premature mortality, and just over half to non-fatal outcomes of morbidity and disability.

3.27 Mental illness has a much bigger impact on the latter, accounting for less than 5% of all premature mortality, but for over 30% of all morbidity and disability. No other single health condition accounts for more than 10% of the total burden associated with non-fatal outcomes. Therefore, in Northern Ireland we are spending 9.3% of our HPSS Budget on mental health when 30% of all morbidity and disability, in fact, can be attributed to mental ill health.

Health Not Disorder

3.28 There is now a growing body of evidence that positive mental health cannot be gained by treating mental disorders alone (WHO 2004). For example, providing the most effective evidence based treatment for one half of all people with depression would only reduce the current burden of depression by less than one quarter. On the other hand, evidence demonstrates that mental health promotion and prevention can lead to health, social and economic gain, increases in social inclusion and economic productivity, reductions in the risks for mental and behavioural disorders and decreased social welfare and health costs (Jane Llopis & Anderson 2005; WHO 2005).

3.29 It is in this context that the Review sets out its findings and recommendations.

THE ACTION

An Education Example

3.30 Although there is a pressing need for robust studies of cost/benefits of specific interventions, there is sufficient evidence to support the case for greater investment in mental health promotion. The clear relationship between poor mental health in children; for example anxiety, depression and behavioural problems, and poor school outcomes, poor physical health, self harm and risk taking behaviour means that even small improvements in mental health contribute to improved physical health, productivity and quality of life (Mental Health Foundation 2005; Meltzer et al 2000; Department for Education and Skills 2001).

3.31 A number of studies are beginning to calculate the economic cost of failing to address early signs of emotional problems in childhood. Scott et al found that the cumulative costs of public services used through to adulthood by individuals with 'troubled behaviour' were 10 times higher than for those with no problems. Conduct disorder was the most significant predictor, with greatest costs incurred for crime, followed by extra educational provision, foster and residential care, and state benefits (Scott et al 2001). One pilot study of children aged 4-8 referred with conduct disorder, found that the mean extra cost was £15,282 a year (range £5,411-£40,896). Of this, 31% was borne by families, 31% by education services, 16% by the National Health Service, 15% by state benefit agencies, 6% by social services, and less than 1% by the voluntary sector (Scott et al 2001).

3.32 The cumulative cost of childhood conduct disorder for each 1-year cohort in the UK is a minimum of £1.9 billion and in all likelihood several times higher. According to the same study on which this figure is based, the cost of a typical parenting programme is around £600 per child. For every cohort of 600,000 children, a population-wide programme would therefore cost £360 million. Is it worth introducing such a programme? This depends on its effectiveness, but one can easily work out that the programme needs to reduce the prevalence of conduct disorder by at most around 20% (and almost certainly only a fraction of this if the full costs of conduct disorder were properly measured) to be a justifiable use of resources (Scott et al).

3.33 The remaining chapters in this Report look at what is required to strengthen the position of mental health promotion in Northern Ireland. It is our hope that this Report will contribute to the debate, encourage appropriate action and lead to mental health promotion becoming a greater priority across all sectors.

CHAPTER 4

DEFINITIONS AND AIMS OF MENTAL HEALTH PROMOTION

4.1 There is a wide range of definitions of mental health. No single definition is likely to be appropriate for all sectors and settings. For the purposes of this Report, with its particular emphasis on the importance of social inclusion and citizenship, we have found the following useful:

"Mental health is the capacity to live life to the full in ways that enable us to realise our natural potentialities, and that unite us with, rather than divide us from all other human beings who make up our world." (Guntrip, 1964) and *"Public mental health; the art, science and politics of creating a mentally healthy society."* (Friedli 2004).

Aims of Mental Health Promotion

4.2 Mental health promotion aims to:

- **Promote mental health and well-being for all,** eg. supporting parents, health promoting schools, workplace, policies.
- **Prevent mental health problems for** at risk groups through increasing protective factors (eg. social support, job control, benefit uptake, employment, and reducing risk factors, eg. racism, violence, bullying, debt, isolation).
- **Promote mental health for people with mental health problems,** eg. reducing discrimination and social exclusion, providing opportunities for meaningful occupation.

Promotion of Mental Health and Well-Being for All

4.3 Mental health is an issue for all of us. The WHO Action Plan (2005) has as its first action area to "promote mental well-being for all" and states:

"Mental health and well-being are fundamental to quality of life, enabling people to experience life as meaningful and to be creative and active citizens. Mental health is an essential component of social cohesion, productivity and peace and stability in the living environment, contributing to social capital and economic development in societies. Public mental health and lifestyles conducive to mental well-being are crucial to achieving this aim. Mental health promotion increases the quality of life and mental well-being of the whole population, including people with mental health problems and their carers. The development and implementation of effective plans to promote mental health will enhance mental well-being for all."

Addressing Inequalities: Promoting Inclusion and Equality of Opportunities via Mental Health Promotion

4.4 Mental health problems are both a cause and a consequence of deprivation and inequalities (Pilgrim & Rogers 2003). Poor mental health is not a random misfortune, but is strongly associated with unemployment, less education, low income or material standard of living, in addition to poor physical health and adverse life events, for example, racial discrimination, bereavement, violence, bullying and abuse (Fryers et al 2003; Melzer et al 2004). Other risk factors include a family history of psychiatric disorder, childhood neglect and family breakdown. Bereavement, financial strain and long-term caring are risk factors across the life cycle, and especially in later life (Milne et al 2001; Godfrey and Denby 2004).

4.5 Stigma and discrimination have been identified as the greatest barrier to social inclusion, quality of life and recovery for people with mental health problems (Social Exclusion Unit 2004). Stigma may also inhibit people from seeking help and contributes to the isolation experienced by many people with mental health problems, their families and carers. Key issues include public attitudes, negative and distorted media coverage, and lack of access to mainstream opportunities eg education and leisure.

4.6 As Williams points out, much stigma and prejudice is based on fear and a wish from a sense of insecurity, to banish differences and retain a sense of "them" and "us" (Williams 2004).

4.7 Recent years have seen a greater focus on tackling stigma and discrimination across the UK, both nationally and locally . In Scotland, the National Programme on Improving Mental Health and Well-being includes a major campaign to challenge stigma; 'See Me' (http://www.seemescotland.org/). The results of the second national Scottish Attitudes Survey are encouraging (Scottish Executive 2004) and point to the high visibility and impact of "See Me" and some positive shifts in attitudes towards those with mental health problems since the last survey two years ago.

4.8 In England, the National Institute for Mental Health (England) (NIMHE) has launched "From here to equality", a 5 year anti-stigma and discrimination programme (NIMHE 2004), responding to the Social Exclusion Unit's report on mental health which found that over 80% of respondents in the research identified stigma as the biggest barrier affecting people with mental health problems.

Long Term Investment

4.9 Long term investment must be predictable and sustainable.

4.10 In addressing the challenge, the WHO Action Plan (2005) cites certain actions as beneficial, such as the adoption of mental health as a long term investment, with education and information programmes having a long timeframe.

4.11 Greater awareness and understanding of mental health issues, together with policies that support mental well-being, for example, in schools and the workplace, can play a significant role in improving day to day experience of people with mental health problems in Northern Ireland.

4.12 Mentally healthy environments such as schools and the workplace can have a very beneficial impact on people's psychological and emotional well-being. Chapter 5 of this Report includes a range of examples, including The Health Promoting School and University/College tackling workplace stress and promoting mental health in communities and neighbourhoods.

The Prevention of Mental Health Problems for At Risk Groups

4.13 In the 2002 Health and Lifestyle Survey, respondents identified experiencing less stress as the factor most likely to improve their health, indicating the high significance that the general population in Northern Ireland attaches to mental well-being (HPA 2005).

4.14 The determinants of both positive mental well-being and mental health problems are complex and include a mix of biological, psychological, social and environmental factors (Table 1). However, the relative contribution of key risk factors such as material deprivation, genetic inheritance, family relationships and adverse life events is difficult to determine. It has also proved difficult to identify the precise causal pathways through which different factors, eg. poverty; family conflict; experience of bullying; misuse of substances, or violence impact on mental health outcomes. Identifying which protective or resilience factors, and at which level (ie. individual, family, community, structural) are of greatest importance in minimising the impact of risk factors is equally challenging.[2] Some examples of interventions designed to reduce risk factors and increase protective factors are outlined in Chapter 5 of this Report.

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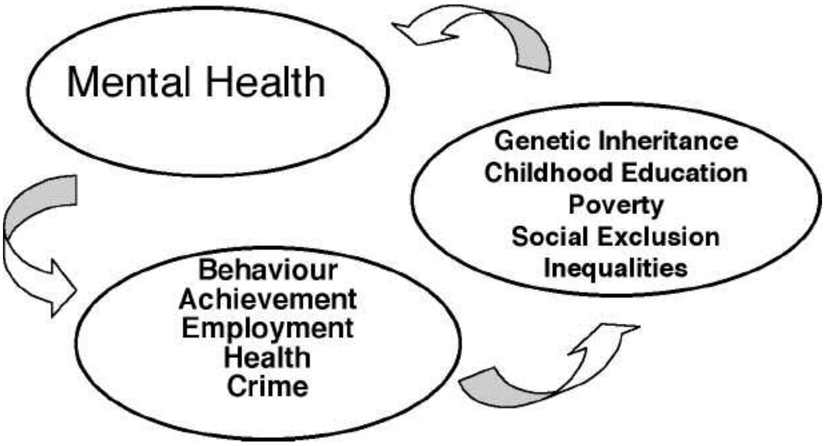
[2] The most up to date source of evidence on risk and protective factors and effective interventions to promote mental health is the National Electronic Library for Health (Mental Health Promotion) http://www.nelh.nhs.uk/nsf/mentalhealth/whatworks/intro/risk.htm

Table 1: Risk Pathways



4.15 There is also growing and increasingly robust evidence for an association between a range of lifestyle behaviours and mental health status and outcomes. These include physical activity, diet, alcohol consumption and the use of cannabis and other psychotropic substances. Certain emotional and cognitive skills and attributes are also associated with positive mental well-being, including feeling satisfied, optimistic, hopeful, confident, understood, relaxed, enthusiastic, interested in other people and in control (Stewart Brown 2002).

4.16 There is also evidence of an increased risk of experiencing common mental health problems such as depression and anxiety amongst people who experience cumulative life stressors, notably material deprivation, family conflict, unemployment and physical disorders (Melzer et al 2004). Other adverse life events which increase risk include workplace stress, bereavement and bullying. People in lower social classes are at increased risk of exposure to such cumulative stressors and also have higher prevalence of common mental health problems – representing the familiar pathways of inequalities in health (Pilgrim & Rogers 2003; Melzer et al 2004).

4.17 The mental health of children is of particular importance because of the strong correlation between emotional problems in childhood and poor mental health and social functioning in later life (Kim-Cohen et al 2003; Meltzer & Gatwald et al 2000). Mental health problems experienced by children and young people ripple out and affect many aspects of the child's life, family and community life, educational achievement and physical health. Timely interventions, including parenting support and effective mental health promotion can reduce the incidence of serious health and social problems in later life (Mental Health Foundation 2005). While there is a clear need to improve child and adolescent mental health services and to strengthen mechanisms for the early identification of emotional problems in childhood, all children have mental health needs and will benefit from a greater focus on emotional well-being in families, schools and the wider community.

Mental Health Promotion for People with Mental Health Problems

4.18 Even those individuals with severe and enduring mental health problems can achieve a good quality of life and feel mentally healthy for much of the time - the illness does not necessarily make this impossible. Mental health promotion can contribute to the reduction of discrimination and social exclusion, helping people to find meaningful occupation, and increase access to mainstream opportunities, all of which can help to improve self esteem, confidence, social networks and overall sense of well-being and quality of life, as well as recovery.

4.19 Mental health promotion is relevant to those with, and those without, a diagnosis, and the many people who move between periods of mental health and mental illness.

The Benefits of Promoting Mental Health

4.20 Mental health promotion aims to improve mental health. Improved mental health will also contribute to improved outcomes for other public health priorities in Northern Ireland, notably coronary heart disease, as well as chronic diseases like diabetes, where there is a strong association between levels of mental well-being and outcome. Poor mental health is associated with poor self management of chronic illness and a range of health damaging behaviours, including smoking, drug and alcohol abuse and poor diet. Stress epidemiology demonstrates the link between feelings of despair, anger, frustration, hopelessness, low self worth and higher cholesterol levels, blood pressure and susceptibility to infection. Both depression and low job control are independent risk factors for coronary heart disease (Brunner & Marmot 1999; Stansfeld et al 2000).

4.21 Mental health promotion therefore has a number of benefits. It can:

- improve physical health;
- increase emotional resilience, enabling people to enjoy life and to survive;
- difficulties and distress;
- enhance citizenship, giving people the skills and confidence to adopt meaningful and effective roles in society;
- improve health at work, increasing productivity and reducing sickness absence;
- help to reduce either the incidence or the severity of mental health problems;
- assist recovery from mental health problems;
- improve quality of life for people with mental health problems; and
- increase the mental health literacy of individuals, or ganisations and communities (adapted from Department of Health 2001).

4.22 There is also a moral argument that the promotion of mental health is worthwhile in itself, and that it is a basic community responsibility to foster mental as well as physical well-being.

What and Who Works to Promote Mental Health?

4.23 Many of the factors that influence mental health lie outside the remit of health and social care. Effective mental health promotion depends on expertise, resources and partnership, across all sectors and disciplines.

4.24 Mental health promotion is also relevant to the implementation of a wide range of policy initiatives, including social inclusion, neighbourhood renewal, community strategies, and health at work.

4.25 Some factors related to improved mental health include:

- **Feelings:** confident, understood, respected, empowered, safe;
- **Skills:** life skills, parenting, relaxation, help seeking, keeping fit, accessing information, problem solving;
- **Meaningful Activity:** employment, volunteering, education, leisure, creativity, spiritual growth;
- **Social Support:** self-help groups, opportunities for friendship, faith communities, home visits;
- **Access to Resources:** paid work, adequate welfare benefits, appropriate services; and
- **Influence:** opportunities to participate, being consulted, shared decision making, advocacy, complaints procedures (Friedli, 2004).

Evaluation of Success

4.26 There is a growing body of outcome indicators to draw upon from research, many of which in fact reflect a number of the resilience factors. Friedli has itemised these under the following headings:

Individuals	Social Capital	Quality of Life
• Agency • Capacity to learn, grow and develop • Feeling loved, trusted, understood, valued • Interest in life • Autonomy • Self acceptance and self-esteem • Optimism and hopefulness • Resilience	• Feeling safe • Trusting unfamiliar others • Participation • Influencing local decisions • Believing the local neighbourhood is improving • Access to local support • Social inclusion • Employment and meaningful activity • Support for parents	• Equity • Control • Involvement • Safety • Lifelong learning • Cultural assets • Environment • Access to services • Inclusion

4.27 The growing evidence base in mental health promotion provides examples of the range of ways in which effectiveness of interventions can be measured.

4.28 The above checklists are useful and reflect new thinking in the field of positive psychology - there is a new legitimacy to the study of human strengths arising out of the principles of prevention and promotion. Increasingly there is a sense of a need to see individual experience, not simply as good or bad, ill or well, happy or unhappy , but to understand something of the subtle complex dialectic taking place in all of us at any given time and how that indeed *'strength is often fired in the crucible of adversity'* (Ryff C.D. & Burton, 2003).

Social Capital and Mental Health

4.29 If one looks more closely at the social capital indicators the political dimensions to mental health become more apparent.

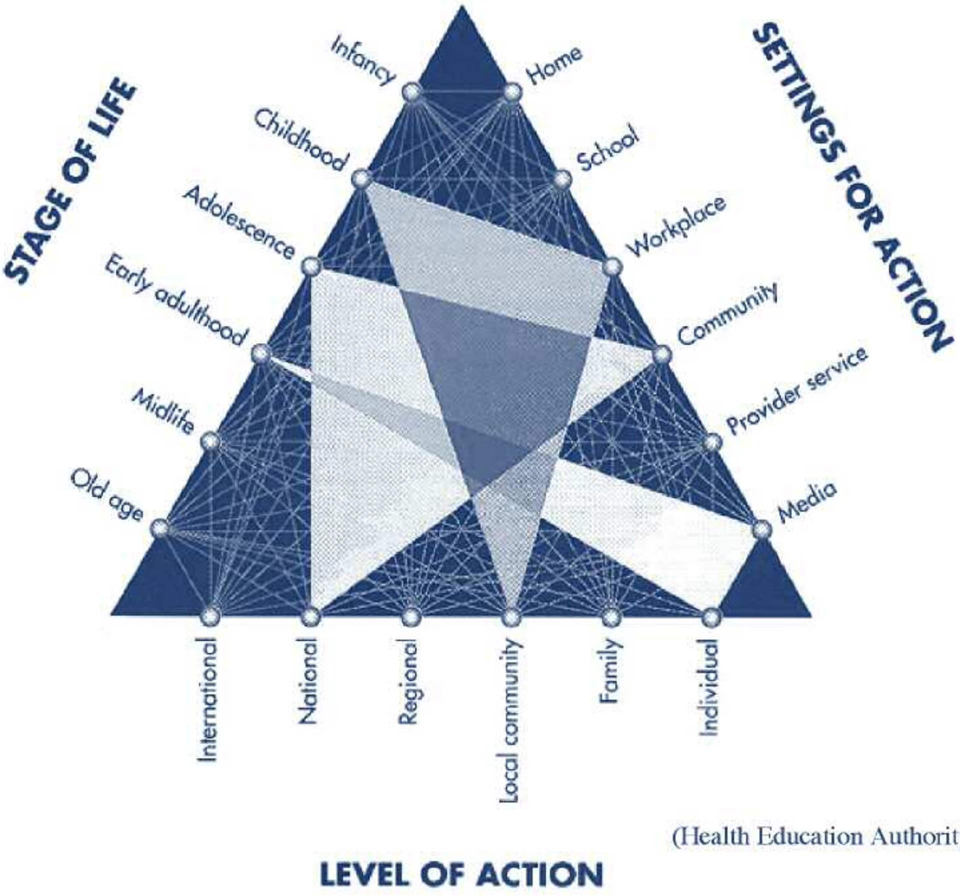
> *"On the one hand, millions of dollars are committed to alleviating ill-health through individual intervention. Meanwhile we ignore what our everyday experience tells us, ie. the way we organise our society, the extent to which we encourage interaction among the citizenry and the degree to which we trust and associate with each other in caring communities is probably the most important determinant of our health"* (Lomas 1998 p. 1181).

4.30 In the renaissance of thinking in recent decades about social collectivity and health promotion, the concept of "social capital" has been prominent. It is invoked to reframe previously individualised lines of research on the social determinants of health generally and mental health in particular . Extending beyond the tools and training that enhance individual productivity ("physical capital" and "human capital"), social capital "refers to features of social organisation such as networks, norms, and social trust that facilitate co-ordination and co-operation for mutual benefit" (Putnam 1995). Economic and social environments also affect social capital.

4.31 Social capital is not an individual perception or resource. Potential detriments include exclusion of non-members and minority groups, and excessive demand on members of social organisations. A consensus is growing, however, that social capital facilitates collective action and can promote social and economic growth and development by complementing other forms of capital.

4.32 Research over the last two decades has demonstrated links between social capital and economic development, the effectiveness of human service systems, and community development. Social scientists have investigated how higher social capital may protect individuals from social isolation, create social safety , lower crime levels, improve schooling and education, enhance community life, and improve work outcomes (Woolcock 1998). Researchers have begun to analyse the relationships between social capital and mental health (Kawachi & Berkman 2001; McKenzie, Whitley & Weich 2002; Sartorius 2003). (WHO, 2004).

CHAPTER 5
IDENTIFICATION OF NEED



(Health Education Authority, 1997)

Introduction

5.1 In this chapter we approach the identification of need by looking at **firstly** the promotion of mental health and well-being for everyone in the population at large and identifying the settings in which this can take place.

5.2 **Secondly**, we have identified some of the key at risk groups within the population and have addressed the prevention of mental health problems within these groups and protective factors which could be employed.

5.3 **Thirdly**, we have considered those who have experienced mental health problems and ways in which their quality of life could be improved.

5.4 The Review is aware that there is a pool of good practice in Northern Ireland. The local examples provided in this Report have been randomly selected. However, we have recommended that one of the priorities of a proposed established Regional Directorate of Mental Health Promotion should be a comprehensive “mapping” exercise.

Promotion of Mental Health and Well-Being for All in the Population at Large

Aim: To promote mental health and well-being for all

5.5 In the first section the emphasis is on different environments, or settings through which the population at large can be reached. Given that mental health is influenced by a range of protective and risk factors, many of which are environmental, these broader factors need to be addressed, not simply focusing on the vulnerable individual.

5.6 Settings include:

- Home;
- School;
- Workplace;
- Communities and Neighbourhoods;
- Further and Higher Education;
- Primary Care;
- Rural Areas;
- Faith Communities; and
- Prisons.

HOME

The Case for Action

Children and Families

5.7 Poor mental health in children, such as anxiety, depression and behavioural problems, is a significant risk factor for poor school outcomes, poor physical health, poor social skills and suicidal behaviour (Mental Health Foundation 1999).

5.8 Factors which promote resilience in children under 5 help those children to do well in spite of adversity (Mental Health Foundation 1999).

5.9 Factors which strengthen resilience include family harmony, co-operation, good relationships between parents, opportunities to succeed, and internal locus of control (Mentality 2002).

What Works?

5.10 Ample evidence exists that early intervention programmes are a powerful prevention strategy. The most successful programmes addressing risk and protective factors early in life are targeted at child populations at risk, especially from families with low income and education levels (Brown and Sturgeon, 2005). They include home-based interventions during pregnancy and infancy, efforts to reduce smoking during pregnancy, parent management training and pre-school programmes.

- **Promoting Parenting Skills** - group based parenting training programmes improve the mental health of both parents and children (Barbour et al 2001) and may be more acceptable to parents than clinic based programmes for individuals/parents.

- **Home-Based Interventions** - evidence from home visiting interventions during pregnancy and early infancy , addressing factors such as maternal smoking, poor social support, parental skills and early child-parent interactions, has shown health, social and economic outcomes of great public health significance (Brown and Sturgeon, 2005). These include improvement of mental health both in the mothers and the new-borns, less use of health services and long-term reductions in problem behaviours after 15 years. Evidence also shows that such interventions can be cost-effective, especially when long-term outcomes are taken into account.

- **Improving the Mental Health of Mothers** - early support during pregnancy for mothers in difficult social and economic circumstances has been shown to have a positive impact on birth weight and family relationships. Professional emotional support for women caring for their existing children can decrease the rate of post natal depression (Hodnett 2000: Scott et al 1999).

Northern Ireland Example

Lifestart Foundation

5.11 Lifestart (www.lifestartfoundation.org) which has offices in Northern Ireland and the Republic of Ireland, is a home based educational programme for parents of children aged from birth to 5 years. Its aim is to enable parents to make informed, relevant decisions about the upbringing of their children.

Key Issues to be Addressed

5.12

- Factors which promote resilience in children under five help those children to do well despite adversity , therefore early intervention is vital. Evidence shows, for example, that Promoting Parenting Skills Programmes improve the mental health of both parents and children. This is an area which should be further encouraged.

- Action 18 of the Strategy and Action Plan 03-08 relates to parenting skills and links with the ongoing work being undertaken to implement the teenage pregnancy and parenthood strategy and action plan.

- According to the Implementation Group' s (Strategy and Action Plan 03-08) Draft Annual Report, all HSS Boards are undertaking some action, for example the delivery of skills training to Surestart staff on building self esteem and handling child behaviour.

SCHOOL

The Case for Action

5.13 It is recognised in the literature that schools can have a vital role to play in protecting the health of young people. Resnick et al (1997) have identified an association with academic failure and lost school days with anti-social behaviour and emotional problems.

5.14 Pryce and Twyble et al (2004) in their paper "Mental Health Promotion Among Young People" state that: *"Schools have a significant influence on the behaviour, attitudes and development of young people"*.

5.15 The Department for Education and Skills in England in their guidelines "Promoting Children: Mental Health Initiatives Early Years and School Settings" emphasises the importance of schools in the promotion of mental health of children.

5.16 The Council for the Curriculum Examinations and Assessment (CCEA) have highlighted issues relating to bullying.

5.17 The regional strategy document "Promoting Mental Health – Strategy and Action Plan 2003-08" identifies specific actions relating to the promotion of young people's mental health. Action 9 within the document refers specifically to pupils' mental health. It states "*Department of Education in partnership with DHSSPS, HPA, schools and the voluntary and community sectors will develop a regional education resource for the promotion of pupils' mental health and emotional well-being including anti-bullying approaches for use in school"*. Target date: March 2004.

What Works?

5.18 Characteristics of the health promoting school include features such as shared decision making and planning; community participation; a supportive physical and social environment; good school – community relations; clearly articulated health policies, and access to appropriate health services.

The Resourceful Adolescent Programme (RAP) - Australia

5.19 This programme was developed to meet the need for a universal depression preventative programme for teenagers that could readily be implemented in a school setting.

5.20 A universal programme targets all teenagers in a particular grade as opposed to those at higher risk of depression. It is easier to recruit and engage adolescents in a universal approach if they do not face the risk of stigmatisation by being singled out for intervention.

5.21 An 11-session programme has been designed to be implemented in the classroom as part of the curriculum. The programme aims to build resilience to depression in pre-teenagers and younger adolescents and has been shown to be effective in reducing rates of depression (Dadds et al, 1997).

The Health Promoting School

5.22 Action has been taken by the HPA to take an initiative forward – that of the Health Promoting School. This initiative, proven to be effective at an international level, offers a vehicle for change in Northern Ireland, but there are issues, such as lack of long term funding and the fact that only 10% of schools have been targeted in Northern Ireland.

5.23 An Office for Standards in Education (Ofsted) Report, in July 2005, refers to the vital role of schools in providing for pupils with mental health needs and the current barriers to this. They refer to the need for whole-school approaches to promoting good mental health.

5.24 In a survey of schools in Great Britain carried out by Ofsted in 2004 (published July 2005, HMI) it was stated that:

> *"The best schools promoted emotional health and well-being by valuing and respecting every individual. In the schools visited, those which introduced a value system that embraced all children identified fewer children with mental health problems. These schools promoted many and varied opportunities for pupils to share their thoughts and feelings. They used the curriculum to develop pupils' listening skills and an understanding of other people's points of view: this culture permeated school life."*

5.25 The CCEA recommend that anti-bullying schemes, in particular those which involve the whole school, parents and community need to be higher on the agenda. These can be effective in dealing with the issue.

5.26 In Northern Ireland, the impact and effectiveness of the initiative is still to be reported on.

Key Issues to be Addressed

5.27
- **School Interventions** - it is recognised that schools can have a vital role to play in protecting the health of young people. Interventions such as the RAP in Australia and the Health Promoting Schools initiatives have been proven to be effective in promoting children's mental health. Proper resources and cross-sectoral working are needed to implement a province-wide schools strategy. Whilst the current work being carried out in Northern Ireland on the Health Promoting School Initiative is valuable and points for the potential for the future, there are important issues which need to be addressed such as:

- **Funding** - a significant source of long-term funding needs to be identified and committed to such projects.

- **Cross-Sectoral Issues** - funding currently comes via the DHSSPS - with no involvement of the Department of Education. For an educational issue such as this, there needs to be a commitment by both the Department of Education and the DHSSPS for it to be successful.

- **Curricular Issues** - there should be a proper curricular approach, with the "Health Promoting School" initiative dovetailing into other existing curricular programmes such as personal development.

- **Training** - teacher training needs to be reviewed, with teachers at the point of entry into teacher training, receiving proper training on mental health.

THE WORKPLACE

The Case for Action

5.28 The workplace is an important environment for the individual. Work can be a source of stimulation, satisfaction and support, leading to an increased sense of well-being and reduced incidence of stress related sickness absence (Sainsbury Centre for Mental Health 2000; Stansfeld et al 2000).

5.29 Yet a negative working environment can lead to a range of problems such as: sickness absence; stress-related problems; labour turnover; bullying and harassment; poor interpersonal relations, and ineffective working.

5.30 A company with 1,000 employees can expect between 200-300 people to experience depression or anxiety in any year (The Industrial Society 2003). The loss of sickness absence attributable to mental health problems was estimated to be £4 billion in the UK in 2001 (Counting the Cost NIAMH, Sainsbury 2003).

The Dynamics of Work Stress

5.31 **Stressors potentially affecting health include:** factors intrinsic to the job such as work over or under load; lack of job control, and repetitive tasks. Factors relating to role in the organisation can include too much or too little responsibility . Relationships may be poor, with even bullying and harassment a factor. Career development pressures may mean over promotion or under promotion. Factors relating to the overall culture and environment of the organisation are very important. If people feel supported and valued at work, with a sense of genuine participation and involvement, there is a lesser likelihood of stress developing even with a large volume of work.

5.32 Finally, the home-work balance can be hard to sustain, with domestic difficulties spilling over into work, and work related stress having a negative impact on home life.

The Legislative Imperative

5.33 Employers are under a general duty to take responsibility to ensure the health and safety of employees whilst at work. The law states that mental health should be viewed in the same light as physical health.

5.34 There are a number of health and safety regulations that are of relevance, in particular:

- Health & Safety at Work (Northern Ireland) Order 1978;
- Management of Health & Safety at Work Regulations 1992;
- Health & Safety (Consultation with employees) Regulations 1992;
- Employment Rights Act 1996;
- Working Time Regulations 1998;
- Safety Representation & Safety Committee Regulations 1977;
- Disability Discrimination Act 1995; and
- Human Rights Act 1998.

What Works?

5.35 The Health and Safety Executive issued a Workplace Health Strategy, (Action 10, Strategy and Action Plan 03-08) which aims to promote mental health in the workplace with specific reference to work related stress.

5.36 Some actions which have been shown to be effective include the following examples:

- **Culture of Openness to Mental Health Issues** - studies have shown that facilitating an environment that generates positive attitudes to mental well-being can help reduce stigma for those experiencing problems.

- **Support at Work** - emotional support can be very powerful. It is a particularly protective factor against high job demands (HSE 2001).

- **Job Control and Decision Making Aptitude -** having control over work reduces the risk of sickness absence (Stansfeld et al 2000). Individuals need to have some influence over decisions made at work at different levels.

- **Mental Health in the Workplace Policy** - having a strong, comprehensive Mental Health in the Workplace Policy outlining the responsibilities of both the individual and organisation, is a key factor.

- **Employee Assistance Programmes (EAPs)** - which provide individual support and counselling, but also address organisational issues via the implementation of stress/organisational audits, risk assessment for mental health and mental health policies, have been shown to be effective in enhancing employees' health and well-being (HEA, 1998).

Key Issues to be Addressed

5.37 Employers have a duty under health and safety legislation to take measures to protect the health of their employees at work.

5.38 A negative working environment can lead to a range of problems such as: sickness absence, labour turnover, bullying and harassment and ineffective working. What helps is to promote a healthy culture, with good quality of relationships, communication and support to staff.

- Policies should approach the topic in a comprehensive way, from recruitment and training, right through to actual support for vulnerable staff and guidance on handling issues such as staff sickness and absenteeism. Training for managers in implementing such a policy is recommended.

- All employers, <u>as a minimum</u>, should have in place a Mental Health in the Workplace Policy which seeks to address, even as a staged process over a period of time, issues relating to prevention of negative factors where possible, and support to those who may be in a stressful environment, or going through a difficult period.

COMMUNITIES AND NEIGHBOURHOODS

The Case for Action

5.39 People with mental health problems are amongst the most excluded groups. Social exclusion is, therefore, a major public health issue.

5.40 Regionally Promoting Social Inclusion (PSI) is an element of the New Targeting Social Need Strategy which focuses on promoting issues to be tackled to improve and enhance the life and circumstances of the most deprived and marginalized people in society.

"The Department has established a cross departmental PSI Working Group on Mental Health which will consider factors that cause people with mental health problems to be at risk of social exclusion and develop a co-ordinated inter departmental study through which relevant agencies will work together to systematically tackle them. This Strategy will support their work" (Investing for Health 2002).

5.41 Section 75 of the Northern Ireland Act 1998 requires public authorities, in carrying out their functions, to promote equality of opportunity between persons of different religious belief, political opinion, racial group, age, marital status, sexual orientation, gender, disability and persons with dependants or without.

5.42 Northern Ireland experiences higher levels of deprivation than Britain or Europe (The Family Expenditure Survey Report for Northern Ireland 1998/99). There is a clear link between poor mental health and living in those neighbourhoods which both are economically disadvantaged and have experienced greater exposure to the "Troubles" (NICORE 1999).

5.43 Various actions with the Strategy and Action Plan 03-08, refer to community development:

Action 5 - *"Health and Social Services (HSS) Boards and Trust through the Investing for Health Partnerships will further develop policies and programmes to promote mental health, taking account of the particular needs of all vulnerable groups including homeless people and victims of the conflict, across all services, and report annually to the Implementation Group"*. Target Date: Ongoing.

Action 11 - refers specifically to the support of *"the development of a rural support network"*.

Action 14 - develops the need for information about local sources of help and support is developed.

5.44 It is to date unclear to what extent these specific actions have been programmed.

What Works?

5.45 Characteristics of communities which promote mental health and well-being include:

- equitable access to resources and services;
- support for parents and carers;
- activities that bring members of the community together;
- effective sharing of local information;
- tolerance and trust;
- friendly physical environment;
- dealing effectively with crime and anti-social behaviour; and
- robust local democracy and opportunities to participate.

Mentality 2003 (Adapted from Department of Health 2001)

5.46 **Strengthening Community Networks** - many community interventions have focused on developing empowering processes and building a sense of ownership and social responsibility within community members. An example of such an intervention is the Communities that Care (CTC) Programme, which has been implemented successfully in several hundred communities in the USA and is currently being adopted and replicated in The Netherlands, England, Scotland, Wales and Australia. The CTC prevention operating system is a field-tested strategy for activating communities to implement community violence and aggression prevention systems (Hawkins, Catalano & Arthur, 2002). The strategy helps communities use local data on risk and protective factors to identify risks and develop actions. To date the CTC system has only been evaluated in the USA, with pre-post designs and comparisons with baseline data involving about 40 communities in each field test. These evaluations have indicated improvements in youth outcomes. Examples include decreases in school problems (30% decrease), weapons charges (65%), burglary (45%), drug offences (29%) and assault charges (27%).

5.47 **Reducing Fear of Crime** - within the Nottingham Social Action Research Programme, a project in the Clifton Neighbourhood Ward shifted focus from a crime/anti-social behaviour enforcement role to community development and building social capital as a way of reducing the fear of crime.

5.48 Training, support, and the development of neighbourhood wardens have led to an increase in feelings of trust and safety, confidence amongst residents and the building of networks and a framework for reciprocity (Nottingham SARP 2002 – Social Action Research Project).

5.49 **Stress Workshops for the General Public** - large scale, self-referral stress workshops are effective in reaching people whose problems are not picked up in primary care. A randomised control trial showed that participants were less anxious, less distressed and more able to cope than those in the control and placebo groups (Brown & Cochrane 1999).

Key Issues to be Addressed

5.50
- Interventions designed to increase social inclusion such as social prescribing should be encouraged as part of community development.
- Actions in the Investing for Health 2002 need to be progressed and assessed.
- Research programmes addressing the needs of marginalized groups need to be resourced, with a view to mainstreaming.
- Training for relevant community and professional agencies on mental health awareness and ways to reduce stigma should be provided.
- The benefits of interventions such as arts on prescription for increasing social inclusion and strengthening communities should be explored especially in particularly disadvantaged areas.
- As the CTC Programme appears to have proved to have successful outcomes, not only in the USA, but elsewhere in Europe and the UK, this approach should be considered in Northern Ireland, especially with its particular needs and often fragmented social networks and lack of cohesion.

FURTHER AND HIGHER EDUCATION

The Case for Action

5.51 There are a number of dimensions to the relationship between learning and mental health. On one level Hammond, in a review of literature, found robust evidence for positive associations between years of education and health, especially relating to depression. Outcomes included improved self-esteem, self efficacy and improved trust.

5.52 The wider benefits of learning include:

- positive associations between education and both physical and mental health;
- learning builds self-esteem, feelings of being in control of one's life, and resilience to stress;
- education that is accessible and makes sense to all members of society will reduce inequalities, challenge prejudices and empower people to keep on learning (Hammond, C (2002) Learning to be Healthy, London Institute for Education).

5.53 Facilitating access to further and higher education opportunities for those who are vulnerable is an important issue in itself and not without its difficulties. Also the further and higher education environment can be a pressured experience even for those not vulnerable due to mental health needs.

5.54 Some key documents published by the Education and Health Sectors include:

- Universities UK (previously CVCP – Committee for Vice Chancellors and Principals), Guidelines on Student Mental Health Policies and Procedures for Higher Education, (June 2000);

- Universities UK, Reducing the Risk of Student Suicide: Issues and Responses for Higher Education Institutions (2002); and

- Royal College of Psychiatrists (RCP), The Mental Health of Students in Higher Education, (January 2003).

Good Practice Example (1)

5.55 **The Health Promoting University** - in 1995 the University of Central Lancashire (30,000 students and 2,000 staff) became one of the first universities in Europe to establish a Health Promoting University (HPU) initiative, (Dooris, 1999).

5.56 The aims are:

- to integrate within the University's culture, processes and structures, a commitment to health and to developing its health promoting potential; and

- to promote the health and well-being of staff, students and the wider community. Its effectiveness depends on an holistic, organisation wide approach, rather than simply focusing on the vulnerable individual, whether student or staff.

Good Practice Example (2)

5.57 **Learning Diversity** – accommodation in Colleges and Universities for Students with Mental Illness.

5.58 **The Canadian Mental Health Association** sets out guidelines for facilitating access to further and higher education for those with mental health needs.

5.59 Support services include:

- an academic coach or "buddy";

- increased outreach counselling services;

- assistance with early problems identified;

- peer support groups, emotional support;

- increased training of faculty on mental health issues; and

- support in disclosing the disability to an instructor/professor.

(Canadian Mental Health Association 1993)

Further and Higher Education – Northern Ireland

5.60 The whole concept of a health promoting university or college is still relatively new – most institutions concentrate largely on student counselling services as the main resource.

5.61 However, two of Northern Ireland's Universities have strategies for the improvement of students' mental health in place:

- The University of Ulster's work through its Mental Health Task Force; and
- Queen's University Belfast (QUB) – Mental Health Strategy whose aims are outlined below.

5.62 QUB's Mental Health Strategy is a comprehensive document, which has five key aims:

- to improve mental health promotion and awareness across the University community, by ensuring an integrated approach to developing strategies and activities for the promotion of good mental health;
- to ensure that all those who contribute to the provision of mental health care have adequate training, supervision and support and are well informed of contemporary good practice commensurate with their level of access to students;
- to develop a greater range of necessary expertise within the counselling service in order to respond more effectively to students' needs;
- to locate individual and organisational accountability for the processes and procedures which will help promote the emotional and mental well-being of students; and
- to identify the key areas of responsibility and support for students who encounter emotional and mental difficulties during their time at university.

Key Issues to be Addressed

5.63
- There are positive associations between education and both physical and mental health. Facilitating access to further and higher education opportunities for those who are psychologically vulnerable is an important issue in itself. In addition it is important for students, especially young adults, to feel supported in a pressured and transitional time in their lives.
- The Health Promoting University/College is an initiative which has been implemented in England. Its approach could be assessed for its usefulness in the Northern Ireland context.

PRIMARY CARE

The Case for Action

5.64 As stated in one Western Board General Practitioner's paper on Mental Health Promotion in Primary Care (Foy 2004):

> "*Opportunities for mental health promotion present themselves to all members of the primary care team, including the general practitioner, health visitor, social worker, community midwife, district nurse, practice nurse, community pharmacist and others*".

5.65 Primary care has a crucial role to play in supporting people with long term mental health problems. Primary care also has a role in early identification and treatment of common mental health problems; notably anxiety, depression and phobias, as well as a wider role in promoting mental health and well-being, along with the promotion of physical health.

5.66 The majority of mental health problems are managed within primary care, where a huge percentage of problems presented are psycho-social. On average, GPs spend 30% of their time on mental health problems. Of all mental health conditions, anxiety and depression take up most of GP's time (Foy 2004).

5.67 Chapter 3 of the Strategic Framework for Adult Mental Health Services Report states that:

> *"There is increasing evidence that investment in primary care actually produces better healthcare outcomes in both primary and secondary sectors. There are fewer inequalities in health when primary care systems are well developed"* (Starfield, B 2001).

5.68 In their briefing paper "Radical Mentalities - Making it Effective - A guide to evidence based mental health promotion" (Mentality 2003), (Friedli 2004) describes new models of primary care offering opportunities to develop services at the interface between primary care and the social population; to reach out to socially excluded groups including refugees, homeless people and those with substance misuse problems, and to address inequalities.

What Works?

Promoting Exercise

5.69 The National Consensus Statements on physical activity and mental health (Grant (ed.) 2000) show that exercise prevents clinical depression and is as effective in treatment as other psychotherapeutic interventions. Exercise also reduces anxiety, enhances mood and improves self esteem.

5.70 Encouraging an active lifestyle also helps reduce isolation and the promotion of social networks.

Social Prescribing

5.71 Social prescribing is a vehicle for offering patients in primary care alternative opportunities for support within the local community. Examples of social prescribing include exercise on prescription, prescription for learning and arts on prescription. Quite widely used for those with mild to moderate mental health problems, positive outcomes can include enhanced self esteem, reduced low mood, opportunities for social contact, increased self efficacy, transferable skills and greater confidence (Huxley 1997: Fox 2000).

Key Issues to be Addressed

Professionals

5.72
- **Training for GPs** - approximately 50% of GPs have no formal psychiatric training and few practice nurses have had such training (Croft 2000 in Foy 2004). As most GPs have opted to go into physical medicine, they may have very little experience of mental ill health. There is a need for better training for GPs.

- **Research** - increased research into the effectiveness of mental health promotion at primary care level is needed.

- **Resources, Targets and Priorities** - with the contracting system, there is the opportunity to target resources for mental health promotion. GPs are particularly well placed due to working within an overall health promotion setting, where potentially mental health promotion can be dovetailed with general health promotion initiatives.

- **Role of Voluntary Agencies** - there should be an increased use of services provided by voluntary agencies and increased direct liaison into primary care priorities.

Public

5.73
- **Support Available/Information Services** - primary care environments could be better used as an information resource, perhaps with access to a practice library with self-help literature.
- **Self-Help** - increased promotion of the ethos of empowerment for those who are vulnerable due to mental health problems would potentially speed recovery.
- **Users' Role in Promoting Mental Health at Primary Care Level** - there are opportunities for mental health service user groups in helping to improve mental health issues within primary care (Foy 2004).

Social Prescribing

5.74
- Social prescribing including exercise, learning and arts on prescription, as an adjunct or alternative to medication have been proved to be effective elsewhere in the UK and internationally.
- There is a need for this approach to be further employed in Northern Ireland.

RURAL AREAS

The Case for Action

5.75 The current regional strategy highlights the needs of people living in rural areas in Northern Ireland:

> *"People living in rural areas may experience particular problems including: social isolation, unemployment, poor housing, lack of public transport and public amenities. In addition, recent years have brought a succession of crises affecting farming which have increased financial stress and led to further job losses".* (Strategy and Action Plan 03-08).

5.76 Action II of the Strategy states:

> *"Department of Agriculture and Rural Development (DARD) and DHSSPS will support the development of a rural support network to develop appropriate interaction strategies in rural communities".* Target Date: Ongoing.

5.77 It is not clear at present to what extent this action has been implemented.

5.78 One study carried out in Ireland: Mental Health Promotion in a Rural Context: Resources and Realities for a Community Based Initiative in Northern Ireland (Barry, O'Doherty et al 1999), was based in the Homefirst Trust, and explored awareness of depression and suicide in rural areas and found the following results:

- levels of awareness about knowledge of depression and suicide were generally high with 80% of respondents aware of the rise in suicide rate in Northern Ireland;
- 43% reported concern in relation to access to mental health services in rural areas;
- 68% reported little confidence in their own ability to advise someone who was suicidal;
- men were significantly less likely than women to believe in the effectiveness of the GP;
- the under 40 year old group was significantly less likely to seek help from a psychiatrist;
- social stigma was a barrier cited to seeking help; and
- 22% referred to reluctance to disclosing problems.

What Works?

The Rural Health Partnership (Homefirst Community Trust, Northern Health and Social Services Board)

5.79 This Partnership aims to deliver a programme of support that aids the reintegration of people who have suffered from mental ill health, back into the home and community life. The programme, which includes training, health promotion and information, has a particular focus on young men, carers and children living with mental illness in farming communities.

Key Issues to be Addressed

5.80

- As rural areas have been identified as being particularly prone to risk factors such as isolation, and specific problems related to the farming community , and are particularly at risk of suicide, a province-wide strategy is required to help raise awareness of issues involved and to help people identify where to get support.
- Stigma has been identified as a major barrier in people seeking help - therefore, a strategy to address issues relating to stigma, especially young men in rural areas should be outlined.
- The actions relating to rural areas in the Strategy and Action Plan 03-08 need to be progressed.

FAITH COMMUNITIES

The Case for Action

5.81 Those with enduring serious mental illness may experience their lives as a process of fragmentation and disintegration. Recovery and well-being needs, therefore, to focus on the restoration of a sense of wholeness. Holistic care needs, therefore, due to the link between mind, spirit and soul, to include care for spiritual needs.

5.82 Spirituality can be defined as "a core set of beliefs and experiences about our relationship to the universe and our place in it" (Clay 1999).

5.83 People experiencing mental health problems seek understanding and meaning. In an age when organised religion is less well supported, it seems even more important to acknowledge this dimension of experience, where people non affiliated to particular faith communities still seek succour and hope.

5.84 Religion and spirituality have proven protective effects for mental well-being, eg.:

- people with spiritual or religious affiliation are up to 40% less likely to become depressed than people who do not have such affiliation, and if they do get depressed, they recover faster;
- depression affects up to 35% of people with a serious health problem or illness. One study that used multi-dimensional measures showed that for every 10 point increase in the intrinsic religion score, there was a 70% increase in the speed of remission from depression; and
- religious/spiritual commitment correlates with lower levels of substance abuse. The risk of alcohol dependency is 60% greater when there is no religious affiliation (Powell, 2000).

5.85 In 1999, the RCP set up a special interest group - Spirituality and Psychiatry. Its aim is to provide a forum for psychiatrists to explore the influence of the major religions which shape the cultural values of the psychiatrist and patient both.

5.86 A growing number of studies emphasise the importance of spiritual beliefs and the value of support from faith communities for people with mental health problems (Mental Health Foundation 2000). Yet there is a need for some caution in being sensitive to cultural mores – other studies have found a resistance to spiritual issues within mental health services, where religious beliefs are sometimes interpreted as symptoms of illness. If a person fears that mentioning their spirituality may be interpreted as a further symptom of their illness, it will block the proven benefits of an holistic therapeutic approach (Friedli. 2000: Clay 1999).

What Works?

5.87 **Spiritual Assessment** - (Swinton, 2001), describes a number of models of "spiritual assessment" involving a dialogue.

5.88 Powell (2000) from the special interest group lists some learning outcomes for training of psychiatrists in spirituality including an understanding of:

- spiritual crises, meditation, prayer and altered states of consciousness, including near death experiences;
- the spiritual significance of anxiety, doubt, guilt and shame;
- the spiritual significance of love, altruism and forgiveness and their relation to mental health;
- the influence of materialistic goals on personal identity and self-esteem;
- the reciprocal relationship between culture and spiritual/religious beliefs and practices and the consequences for psychiatric practice;
- how to take a spiritual history from a patient;
- how the presence or absence of spiritual/religious beliefs and practices in mental health care workers may influence decision making; and
- the role in clinical management of spiritual/religious support networks, including chaplaining and pastoral care as well as those in the community.

Key Issues to be Addressed

5.89

- An accepting and non judgmental attitude needs to be promoted - those in a caring role need not always "do" anything except listen and afford the individual dignity and respect.
- Training in mental health would be beneficial for those being ordained in all denominations.
- Information/workshops should be provided for those in the community who may benefit from pastoral care, and may not be affiliated to any particular faiths.
- The wider dissemination of the work of the Special Interest Group On Spirituality within the RCP may benefit practitioners not currently involved.

PRISONS

The Case for Action

5.90 The Review's Forensic Services Expert Working Committee highlights the issues relating to the prison environment and mental health. It is a major challenge to provide effective healthcare within a prison environment. Many prisoners have emotional difficulties and may have been subjected during their earlier lives to trauma and neglect. In adult years they may have difficulty coping, have impaired relationships and poor integration into society arising from underlying personality difficulties or disorders. Alcohol or other substance misuse, self-harm and frequent previous contact with mental health and learning disability services are common.

What Works?

5.91 Issues being considered by the Forensic Services Expert Working Committee include the following:

- creation of a prison environment that actually promotes health; and
- provision of a range of mental health and learning disability services.

Key Issues to be Addressed

5.92
- It is a major challenge to provide effective mental health care within a prison environment.

THE PREVENTION OF MENTAL HEALTH PROBLEMS IN KEY AT RISK GROUPS

Aim: To prevent mental health problems through increasing protective factors

5.93 The Review felt it important to identify those particularly at risk in terms of their mental health. Some of these groups, such as young men at risk of suicide, have been also highlighted in the Strategy and Action Plan 03-08.

5.94 There are other key groups which have their own special needs, such as those with Autistic Spectrum Disorder (ASD), which has been the subject of detailed consultation as part of a wider review.

5.95 The main aim of interventions with at risk groups is to increase protective factors (eg. social support, job control, benefit uptake) and reduce risk factors (eg. racism, violence, bullying, isolation, etc).

5.96 Some of the key groups identified as at risk:

- children and adolescents;
- people who are deaf or hard of hearing;
- people with learning disability;
- ethnic minorities;
- older people;
- people who are affected by unemployment;
- people with a physical illness;
- people with gender and sexuality issues;
- people traumatised by sexual abuse; and
- people within the criminal justice system.

5.97 In addition to identifying needs, good practice, and making recommendations relating to different settings and mental health promotion, we feel it important to highlight at risk groups of which we are currently aware.

CHILDREN AND ADOLESCENTS

The Case for Action

5.98
- Around the globe, up to 20% of children and adolescents suffer from a mental illness, with 3-4% requiring treatment. Suicide worldwide is the third leading cause of death in adolescents (WHO, 2003).
- Research indicates mental health problems such as sleep disorders, stress, anxiety and behavioural problems affect 1 in 5 adolescents (HPA 2000).

5.99 Risk factors which may compromise mental health amongst young people include:

- lack of bonding and appropriate attachments;
- family or community conflict or tension;
- feelings of isolation;

- lack of self esteem;
- negative peer pressure;
- poverty and poor physical environment; and
- difficult life events (Strategy and Action Plan 2003-08).

What Works?

5.100 **Pre-School and Psychological Interventions** - there is strong evidence that early interventions starting at age two that promote basic reading skills and engage children in conversations with their parents about picture books, improve reading skills and facilitate the transition to school (Valdez-Menchaca & Whitehurst 1992).

5.101 Within the Review there is an Expert Working Committee on Child and Adolescent Mental Health, which will report in detail on issues relating to children and young people.

5.102 **Mental health literacy and help-seeking at onset of disorder** - given the high prevalence of mental health problems in young people, the fact that the 12-26 year age range represents the peak period for onset of mental disorders across the lifespan (Moon, Meyer & Grau, 1999; Patton, 1996), and evidence that early detection and treatment of depression and psychosis improves outcomes (Kupfer, Frank & Perel, 1989), population-based, indicated prevention and early intervention strategies may provide valuable opportunities to minimise the considerable burden of these disorders.

Young People in Community Settings

5.103 The school setting has been discussed earlier in the Report in terms of its role in promoting young people's mental health. There are also opportunities to promote the mental health of young people outside the school setting and to work with networks of young people in the community. This is particularly important as children grow older and often spend more time with their friends than with their family (Morrow 2002). Peer group pressure is particularly significant in early adolescence (Heaven 1994).

5.104 Social skills training - eg. coaching and cognitive problem solving is particularly effective with isolated children (Erwin 1994).

Good Practice Example

5.105 **The "Insight" Project in Plymouth** is currently being fully evaluated by the Sainsbury Centre. The Project aims to minimise the barriers young people face when they have complex needs. The service is delivered at street level where young people can access it directly in a non-stigmatising environment.

Key Issues to be Addressed

5.106 In terms of mental health promotion, early intervention and the development of emotional resilience have been identified as crucial in helping young people cope with pressures through adolescence into early adulthood.

- There is a range of potential interventions, school, home and community based which can be effective in this regard. Social skills training, eg. involving coaching and cognitive problem solving approaches is particularly effective with isolated children.
- The education and health sectors need to collaborate further on programmes with children and young people.
- Peer education and support can be a relatively cost effective approach, with considerable positive impact.

5.107 The Expert Working Committee on Child and Adolescent Mental Health will report in detail on issues relating to this target group in their report. Members of this Committee discussed with the Mental Health Promotion Expert Working Committee some of the main issues they seek to address in their report which include:

- child and mental adolescent health needs to be society's agenda - not just a healthcare issue solely;
- the education and health sectors need to work together;
- early attachment and infant mental health is important in later life;
- there should be quick and appropriate referral procedures in the event of first onset psychosis;
- there are significant gaps in child and adolescent services;
- "Looked After" children is an issue itself;
- access to support is important to young people - there is potential in peer education approaches;
- there is a regional strategy; - "Bright Future" but not enough emphasis on children;
- there needs to be ministerial commitment to drive any such strategy forward; and
- other international and national models can be useful to draw upon, eg. New Zealand's Diversity Model and the Scottish "Pathway" approach.

PEOPLE WHO ARE DEAF OR HARD OF HEARING

The Case for Action

5.108 There are almost 9 million deaf or hard of hearing people in the UK (Royal National Institute for the Deaf 2005). It is estimated that up to 40% of deaf or hard of hearing people experience a mental health problem at some point in their lives. Yet most deaf people seeking access to mental health care have to overcome considerable barriers to access services that meet their needs (NIMHE/DH, 2005).

5.109 Many of those barriers are caused by lack of information and knowledge about deafness and its implications when assessing and treating mental health problems (NIMHE/DH (2005) Mental Health and Deafness Towards Equity and Access: London).

5.110 The degree of hearing impairment is not directly related to the likelihood or severity of mental health problems. Deafness can lead to a greater sense of identity within the deaf community.

5.111 Deaf people benefit from deaf-aware service provisions, when staff are welcoming, have effective communication skills, understand when to provide sign language interpreters or other language professionals to support communicants and know how to work with them.

People with Acquired Deafness

The Case for Action

5.112 Deafened people are in a totally different situation from those with pre-lingual deafness, who to a great extent are a recognisable community with their own language (signing) and culture. They are also clearly distinguishable from the vast majority of people with a hearing loss - those who develop a mild to moderate loss (usually in later life) who can often obtain much benefit from hearing aids.

5.113 The needs of deafened adults are rarely given attention despite the fact that for every deaf person using sign language, there will be at least three deafened people. These individuals have a much higher incidence of reactive depression than either the general population, or the deaf community and will encounter barriers when attempting to use resources for mental health needs because of the communication difficulties.

5.114 There is little literature on the psychological effects of acquired profound deafness. Most research focuses on the effects of mild or moderate hearing loss or the experience of those who are born deaf (Wood, 1987).

What Works?

Good Practice Example

The LINK Centre for Deafened People, Eastbourne, East Sussex

5.115 **The LINK Centre for Deafened People, Eastbourne, East Sussex** was established in 1972, and is the only centre in the UK providing specialist intensive rehabilitation to groups of deafened men and women. LINK runs week-long programmes, which aim to assist adjustment to deafness and to improve the quality of life for individuals and families affected by deafness (www.linkdp.org).

Peer Education

5.116 The process model that LINK adopts is that of peer education, whereby the focus of the programme centres on the lived experience of deafened people dealing with problematic communication situations. Most facilitators are deafened themselves (or lead sessions with their hearing partner) and many have attended a LINK programme in the past. It is immensely important that participants meet people who have gone through similar situations as themselves and who have managed to sustain a positive life. Facilitators have first hand knowledge about the problems and can provide valuable insights.

5.117 Although focusing on rehabilitation, the approach is very much concerned with the whole person and the promotion of health and emotional well-being in a social context. Therefore, it is very much a mental health promotion intervention.

Key Issues to be Addressed

5.118
- One good practice example, from which Northern Ireland could learn, is that of the peer education process model adapted by the LINK Centre in Eastbourne.
- There is a need for research into this area in the UK generally and Northern Ireland in particular.
- Programmes to increase understanding and awareness of the issues relating to various types of deafness need to be implemented.

(Refer to A Strategic Framework for Adult Mental Health Services – June 2005 section on Services for Deaf People with Mental Health Problems).

PEOPLE WITH A LEARNING DISABILITY

The Case for Action

5.119 People with a learning disability can experience the same range of mental health problems in virtually all categories of psychiatric disorders. It is estimated that 20-50% of those with a learning disability may have a mental health problem (Bouras 2003).

5.120 It is important to implement active mental health promotion strategies for people with a learning disability and their families. A proactive preventative approach would be characterised by promotion of positive mental health from childhood onwards; a multi-agency partnership between health, social care and education; targeted support at times of change; social networks; dedicated access to services and improved awareness of mental health issues for people working in all services providing for people with a learning disability.

What Works?

5.121 A mental health promotion approach, helping to build resilience and other protective factors is recommended. In his paper Mental Health Promotion for People with a Learning Disability, Devine lists 15 recommendations for action. He emphasises promoting positive health from childhood; the need for a multi-sectoral partnership between all relevant agencies; responsibility to enhance well-being and build resilience as a central component of any school curriculum; support at transitional times; enhancing social networks; improved access to services and awareness in staff with learning disability of mental health issues (Devine, 2004).

5.122 “Count Us In” - the Report of the Committee of Inquiry (1998) into meeting the mental health needs of young people with a learning disability is an excellent source of information and examples of good practice in this field.

5.123 Outlined below are 2 evidence based examples taken from the document:

Oaklands College - students with a learning disability are part of the college and are entitled to a common curriculum. Equality is about matching the education to particular needs to deliver that entitlement. Delivering this curriculum requires strategic planning and a multi-agency approach. Other agencies have to sign up, because putting the package together will identify needs and highlight gaps in the care provided.

Community Involvement Project, Larkhall near Glasgow - the Project was set up in 1999 to provide training for employment to adults who have a learning disability . It took 5 years and 386 meetings to get agreement to set up.

5.124 Forty six people with a learning disability use the Project. All start part-time and 23 students are on site at any one time. The students receive a varied programme of laundry, kitchen and catering activities and develop confidence, which results in them undertaking customer service tasks in the tearoom. They are also involved in undertaking Scottish Vocational Qualifications in a range of activities. Six students have so far gained employment, but there are issues of benefits versus income (Count Us In, 1998).

Key Issues to be Addressed

5.125 The Learning Disability Expert Working Committee has reported in detail on these issues. (Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland, September 2005)

5.126 Devine (2004) outlines 15 recommendations for action. These include:

- the need for mental health promotion for people who have a learning disability to be made more specific in mainstream strategies and policies;
- emphasis should be given within all relevant sectors to building positive mental health;
- a responsibility to enhance emotional well-being and build resilience should be a central component of any school curriculum; and
- there needs to be a recognition that people with a learning disability need to have improved opportunities for meaningful work/vocational opportunities.

ETHNIC MINORITIES

Culture and Mental Health

5.127 Although the qualities included in the concept of mental health may be universal, their expression differs individually, culturally, and in relation to different contexts. It is necessary to understand a particular community's concept of mental health before engaging in mental health promotion. The broad nature of mental health also means that it is not just the preserve of the mental health professionals.

The Case for Action

5.128 The Strategy and Action Plan 03-08 takes into account to some extent the needs of ethnic minorities. There are 2 actions (16 and 17) which refer to the DHSSPS, HSS Boards and Education and Library Boards charging them with the task of:

> *"carrying out a review of professional training to ensure that the promotion of mental health and emotional well-being is fully included and takes account of the particular needs of disadvantaged groups including ethnic minority, disability and sexual orientation".*

5.129 One report, published by the University of Ulster in 1997, "Ethnic Minorities in Northern Ireland" looked at the then 4 main ethnic minorities in Northern Ireland – the indigenous travelling community, the Chinese, Indian and Pakistan communities.

5.130 The report highlights Northern Ireland's particular cultural environment due to the Troubles in Northern Ireland:

> *"the long drawn out inter group conflict in Northern Ireland between the two major communities has tended to occlude the existence of a vibrant and growing ethnic pluralism within Northern Ireland".*

5.131 It points out that the understanding of community relations has related the two major communities.

5.132 The report did not seek to assess levels of mental health in the 4 communities, but experience of harassment and prejudice (risk factors for mental health) was experienced, particularly in the Chinese community:

- 44% experienced verbal abuse;
- 50% had received criminal damage to their property;
- 61% believed there was racial prejudice in Northern Ireland and half of all interviewed believed that this trend would increase rather than decrease over time.

5.133 **Better Access to Services** - one of the greatest problems experienced by the ethnic groups was in accessing services, particularly due to language difficulties.

5.134 **Better Opportunities for Training and Employment** - Chinese and Travelling Communities interviewed in the report experienced some difficulties in accessing training and employment opportunities. It was suggested that consultation should take place to see whether a role for employment bodies exists in expanding employment choices.

What Works?

5.135 There are a number of examples of good practice in the rest of the UK.

5.136 **Assertive, But Sensitive - Advice Shop Black** - black people with mental health problems benefit from the work of assertive outreach teams, provided team members are experienced, understand users' concerns and avoid race stereotyping (Duff, 2000).

5.137 **Culturally Sensitive Mental Health Services Through Quality Improvement (2000)** - an urban mental health service undertook a quality improvement programme to involve staff in the identification and resolution of cross-cultural issues. The programme involved clinical file audits, staff surveys and workshops, and a focus group for consumers and their carers. It was found that non-English speaking patients received a different spectrum of services from English speaking patients. Non-English speaking patients were found to receive more pharmacological treatments and less cognitive behavioural therapy . In seeking to address these issues and improve their service delivery to all patients, the mental health service is now in the process of developing cross-cultural training; revising policies and procedures; and engaging bilingual mental health counsellors in a revision of their roles, particularly to increase their availability to staff as cultural consultants.

Key Issues to be Addressed

5.138
- There is a need for greater public education and awareness about ethnic minorities in Northern Ireland.
- There is a need to further explore issues relating to the mental health of these groups.
- Research into identification of need would help to begin to address how to reduce barriers and increase social inclusion for the increasing number of ethnic groups in Northern Ireland.

OLDER PEOPLE

The Case for Action

5.139 The elderly represent an important group within the population. The number of older people within the UK has increased from 1900 when there were 1.7 million people over the age of 65, to 1994 where there were over 8.8 million in this age group (Jenkins & Paykel 1994).

5.140 This increase is projected to continue – by the middle of the 21st century there will be in excess of 12 million older people in the UK. The prevalence of mental health disorders is relatively high in later life. About one third of all admissions to psychiatric care involve people over the age of 65, as do one third of referrals to community oriented mental health services.

5.141 The Strategy and Action Plan 03-08 outlines some factors potentially negatively affecting older people's mental health such as adjustment problems to socio economic difficulties associated with retirement, isolation and decline in social activity; bereavement and loss, mobility problems, and less support due to smaller families.

5.142 With an increasing elderly population, this is a group whose needs (often quite complex) must be addressed. The Review's Expert Working Committee on Dementia and Mental Health Issues of Older People will be reporting on this.

5.143 Action 19 - seeks HSS Boards and Trusts to develop programmes in collaboration with voluntary and community sectors around at improving coping strategies, particularly around time of bereavement.

5.144 Prevention of psychiatric disorder in the elderly will have major benefits for individuals and the community.

Depression

5.145 Depression is the most common psychiatric disorder of late life affecting 15% of the 65 year age group. Unresolved depression is associated with reduced life expectancy and death.

What Works?

5.146 Prevention of physical ill-health and programmes to prepare people for the inevitable changes in later life, such as retirement, loss and bereavement, should in theory reduce the incidence of depressive mood and other affective changes. Many programmes which have been identified as being effective in promoting mental health in the general population should also be available to older people; notably exercise, social support. and arts for creativity.

5.147 Pre-retirement programmes have been seen to be of value. In brief, below are some examples:

- **Pre-Retirement and Older People** - these programmes, often involving group activities, discussion, etc. can alleviate isolation and loneliness. Also, bereavement support and counselling have been found to be effective (Cattan 2002).

- **Telephone Support** - a telephone based support source provided through the Social Work Service in the USA concluded that this sort of outreach strategy was moderately affective by targeting older adults with depressive symptoms, social isolation and unmet needs (Morrow et al 1998 – Randomised Critical Trial).

- **Preventing Suicide in Later Life** - an evaluation on initiatives to identify and prevent elderly suicide at the Centre for Elderly Suicide Prevention, USA concluded that community agencies with specialised programmes for older adults showed promise (Fiske & Arbore 2000 – Controlled Trial).

Dementia

5.148 Dementia is the second most common psychiatric disorder among the elderly. It is a syndrome characterised by an acquired impaired imperative memory and other cognitive functions, changes of personality and a progressive erosion of social skills. The most common causes of dementia are senile dementia of the Alzheimer’s type, and vascular dementia.

Prevention of Dementia

5.149 Strategies for prevention include the avoidance, early detection and treatment of those physical illnesses or other psychiatric disorders which produce dementia-like syndromes.

Ageing Mentally Healthy

5.150 Different types of universal, selective and indicated interventions have been successful in improving the mental health of elder populations (Jané-Llopis et al 2005). Exercise interventions and improving social support through befriending are examples of universal strategies.

Exercise Interventions

5.151 Recent cross-sectional studies and controlled trials have suggested that exercise, such as aerobic classes and t'ai chi, provides both physical and psychological benefits in elder populations (eg. Fox 2000). These benefits include greater life satisfaction, positive mood states and mental well-being, reductions in psychological distress and depressive symptoms, lower blood pressure.

Enhancing Social Support

5.152 Some studies suggest the positive effects of friendship on the mental well-being of older people, especially older women. Befriending is a widely used strategy to increase social support and to reduce loneliness and depression among the elderly. So far only one quasi-experimental outcome study is available confirming that befriending programmes for older women can significantly reduce loneliness and increase the making of new friends (Stevens & van Tilburg, 2000). Replication studies are urgently needed.

Key Issues to be Addressed

5.153
- The prevalence of mental health disorders, such as depression, is relatively high in later life. Programmes such as pre-retirement, the provision of telephone support and prevention of suicide in later life should be implemented within the community.
- Community development programmes should be developed to enhance levels of social support for older people.
- Exercise on prescription through primary care should be encouraged.

PEOPLE AFFECTED BY UNEMPLOYMENT

The Case for Action

5.154 There is a higher level of unemployment and associated deprivation in Northern Ireland than in the rest of the UK (Strategy and Action Plan 03-08). The proportion of long-term unemployed males is higher (29.5%) than in Britain (17.6%). The unemployment rate here for males under 30 years of age is 9.6% compared to an overall rate of 6.2% (Strategy and Action Plan 03-08).

5.155 Unemployment and deprivation are risk factors for mental health. People with mental health needs often experience difficulty in gaining employment despite the fact that disability discrimination legislation forbids exclusion solely on the grounds of evidence of a mental illness.

5.156 PSI is an element of the New Target Social Need Policy which focuses on a sense of priority issues to be tackled to improve and enhance the life and circumstances of the most deprived and marginalized people in society.

5.157 There is not, however, a specific action within the Strategy and Action Plan 03-08 which addresses the issue of unemployment, despite acknowledgement in the document that, eg. 60% of suicides in Northern Ireland were those who were either unemployed, or on long term sick.

What Works

5.158 **Job Clubs** – a number of intervention programmes have been developed and tested for effectiveness in helping unemployed workers return to paid employment, such as the Job Club and the JOBS Programme (see review by Price & Kompier, 2005). These low-complexity and low-cost programmes combine basic instruction on job search skills with enhancing motivation, skills in coping with setbacks, and social support among job seekers. The JOBS programme has been tested and replicated in large-scale randomised trials in the USA (Caplan et al 1989) and Finland (Vuori et al 2002). It has been shown to have positive effects on rates of re-employment, the quality and pay of jobs obtained and increases in job search self-efficacy and mastery and to reduce depression and distress.

5.159 In Northern Ireland, there are a number of Occupation Therapy (OT) led Job Clinics which are run locally in partnership with employers (eg. Foyle Trust).

Employment Support and Placement Services

5.160 **New Horizons Employment Service - Action Mental Health -** it provides a specialist placement and support service for individuals recovering from mental ill health in a variety of work, education and training settings.

5.161 **The Employment Service** - operates from 12 locations throughout Northern Ireland. The Service provides its expertise to theACCEPT Centres and works in partnership with 21 Job Clinics.

5.162 **The Mental Health Promotion Awareness Unit** - in South London and Maudsley NHS Trust works especially to address the problems that people have in accessing services and employment in the community as a result of their mental health problems. The Unit offers mental health awareness training to key local agencies, involving service users in its delivery. The aim is to reduce the stigma linked to mental health problems (Mentality 2002).

Key Issues to be Addressed

5.163
- Given Northern Ireland's higher levels of deprivation and unemployment, any regional strategy should directly address these issues with suggestions for strategic cross-sectoral action.
- It is essential for employers to have more education and awareness of mental health issues to ensure there is no discrimination against individuals seeking employment who have a background of mental illness.
- Any Northern Ireland strategy on prevention of suicide should include specific reference to dealing with unemployment (eg. it has been calculated that if there were full employment in the UK, the suicide rate would drop by 11%) (Lewis, Hawton & Jones 1997).
- Interventions with a strong focus on job search, self-efficacy, social and emotional coping skills and building social support should be encouraged.

PEOPLE WITH A PHYSICAL ILLNESS

The Case for Action

5.164 Mental well-being cannot be separated from physical well-being. Mental and physical illness represent crucial parts of life that are deeply interdependent. Examples are:

Diabetes - diabetes can have a significant impact on the quality of life for individuals, their families, friends, carers and wider society . The emotional and social effects are often underestimated. People with diabetes are more likely to experience anxiety and depression.

Cancer - there can often be uncertainty and distress associated with the diagnosis and treatment of the illness. There is likely to be significant impact on the family, occupational and social environments. The illness and its treatment may cause fatigue, worry and mood change.

Cardiovascular Distress - there is a circular relationship between heart disease and depression. The presence of each increases the risk of the other . A rational health promotion strategy should take account of both physical and mental health needs in seeking to support lifestyle changes, both before and after the diagnosis of heart disease.

5.165 Primary care has many demands on its resources, however, it seems particularly important for primary health case practitioners to be fully aware of the mind-body link (Foy 2004).

Key Issues to be Addressed

5.166 Mental health and physical health are deeply interdependent. For the integration of mental health into general health care to be successful policy makers and practitioners both need to be fully aware of the mind-body link. This is of particular importance at primary care level. Training is recommended for GPs and other professionals in mental health awareness.

5.167 For the integration of mental health into general health care to be successful, policy-makers need to consider the following:

- general health staff must have the knowledge, skills and motivation to treat and manage people living with mental disorders;
- there needs to be sufficient numbers of staff with the knowledge and authority to prescribe psychotropic drugs at primary and secondary levels;
- basic psychotropic drugs must be available at primary and secondary care levels;
- mental health specialists are required to provide support to monitor general healthcare personnel;
- effective referral links between primary, secondary and tertiary levels of care need to be in place;
- investment in primary and community care can deliver better outcomes both in primary and secondary care; and

- recording systems need to be set up to allow for continuous monitoring, evaluation and updating of integrated activities (WHO 2001 World Health Report).

PEOPLE WITH GENDER AND SEXUALITY ISSUES

The Case for Action

5.168 There is considerable evidence of discrimination and bullying of gay people. In Northern Ireland the problem has been identified through two studies (Birkett & Foyle Friend School Survey and White & McCracken 1999). There is much work to be done in helping the whole community understand issues of sexual identity and orientation.

5.169 The Strategic Framework for Adult Mental Health Services also outlines some of the needs of this group (Sect. 6.55, P126).

5.170 Research commissioned by the Department of Education in 2001 indicates that between 2% and 10% of the population in Northern Ireland may be lesbian, gay or bisexual.

5.171 One study points to the level of homophobic bullying of both lesbian, gay and bisexual young people at school.

- 75% of gay men experienced homophobic bullying at school. (Birkett, S & Foyle Friend School Survey "The Experience of Lesbian, Gay & Bisexual People at School in the North West of Ireland").

5.172 Another source quoted in the Strategy and Action Plan 03-08 also highlights bullying as an issue:

- 52% of gay men had been bullied at school;
- 64% of gay men who were bullied at school considered committing suicide;
- 25% of gay men had been sexually assaulted and only 27% of these had received subsequent counselling; and
- 48% of those who had been sexually assaulted had considered committing suicide. (White, R G, McCracken and the Rainbow Project – How Hard Can it Be? – Attempted Suicide of Gay Men – the Psychological Stressors and Associated Risk Factors, Rainbow Project 1999).

Key Issues to be Addressed

5.173 • The psychological and emotional distress of young gay men appears to be reasonably well documented. A gap in identified need seems to be that of young lesbian women's emotional and psychological needs.

- Given that questions over sexual identity can arise in adolescence and early 20’ s, awareness amongst staff in school and further/higher education of these individuals’ particular needs seems vital.

- Public education and awareness of gender issues to promote understanding and tolerance of them is required.

- Youthnet recommend as a result of their research, that lesbian, gay and bisexual training awareness training programs to all those involved in the development, and implementation of services to gay people should be delivered.

PEOPLE TRAUMATISED BY SEXUAL ABUSE

The Case for Action

5.174 Sexual abuse isolates and significantly destabilises lives. Victims are substantially more likely to have mental health problems (Search 1989). 18% of psychiatric patients have been sexually abused girls/women who report sexual abuse are at a substantially increased risk of alcohol and substance abuse disorders (Hefferman et al 2000).

5.175 At least 60% of clients attending the Nexus Institute in 2005 were being treated for depression and anxiety. Others present with eating disorders, alcohol and substance abuse and some have quite serious mental problems.

Key Issues to be Addressed

5.176
- The importance of sex education in schools needs to be highlighted.

- Sexual abuse should be talked about more openly, especially as many forms of abuse are linked to mental health problems.

- As sexual crimes are seriously under reported, training should be given to key relevant professionals in helping to identify hidden issues such as abuse and managing the disclosure of the same.

PEOPLE WITHIN THE CRIMINAL JUSTICE SYSTEM

The Case for Action

5.177 A number of reports have recently highlighted issues within the criminal justice system in Northern Ireland. These include: the Human Rights Commission Report into conditions for women prisoners; the subsequent report by the Chief Inspector of Prisons and, more recently, Professor McClelland’ s Inquiry (A Review of Non-natural Death in Northern Ireland Prison Service Establishments: June 02 - March 04) into the deaths of 6 prisoners.

Prevention of Offending and Re-Offending

5.178

- Two thirds of men in prison are diagnosed with a personality disorder and two fifths show symptoms of at least one neurotic disorder such as depression, anxiety and phobias. Among the general population less than a fifth of men are affected by these disorders.

- Men in prison have a high rate of severe mental health problems such as schizophrenia or delusional disorders – nearly 10% compared to less than 1% of the general population.

- One in five men in prison are on prescribed medication such as antidepressants or antipsychotic medicine and there is evidence that use of medication increases whilst in custody.

- One in five male prisoners have attempted suicide at some stage in their life and the same number have previously been admitted for inpatient psychiatric care (MIND, 2004). Ref. MIND & Prison Reform Trust Conference, May 2004; "Troubled Inside" – Responses to the Mental Health Needs of Men in Prison.

- Women's mental health needs also need to be addressed, particularly because women in prison are nearly always the primary carer and often single parents (Prison Reform Trust 2004 – "Young Parents from Custody to Community").

- The Forensic Services Expert Working Committee will outline in detail the issues with recommendations for actions.

What Works?

5.179 Cognitive behavioural programmes, real life skills and generic problem solving skills are effective in reducing or preventing youth violence. Individual analytical therapy, psychiatric and intensive counselling are deemed less effective or not effective.

Key Issues to be Addressed

5.180 It is recommended that it would be beneficial to take such action as:

- focusing on early intervention;

- research needs to be conducted into the mental health needs of women within the criminal justice system;

- encouraging the courts to use alternatives to custody for men with mental health problems who have committed minor offences;

- increase the number of court diversion schemes available across the country so that offenders who are acutely, ie. not at risk of suicide, can be given hospital places or the treatment they need;

- ensuring the Prison Service meets NHS Standards, policies and protocols, particularly regarding the use of medication, service user initiatives, training for doctors and health care staff; and

- continuing to explore in Northern Ireland, the Restorative Justice Model which has also been proven to be effective as an alternative to long-term imprisonment.

IMPROVING THE QUALITY OF LIFE FOR PEOPLE WHO HAVE EXPERIENCED MENTAL HEALTH PROBLEMS

Aim: To improve quality of life for people with mental health problems

5.181 Improving the quality of life for people with existing mental health problems by reducing discrimination, social exclusion, and by maximising skills and opportunities for employment is a third vital area for mental health promotion.

Quality of Life Approach

5.182 Quality of life is defined by WHO as *"an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns"* (WHO Quality of Life Group 1995). This definition reflects a broad view of well-being encompassing the person's satisfaction with social, environmental, psychological, spiritual and health status. The concept of quality of life describes health, including mental health, in terms that capture positive as well as negative aspects of coping, resilience, satisfaction, and autonomy, among others.

5.183 Those identified include:

- people with enduring mental illness;

- people with eating disorders;

- people at risk of suicide;

- people emotionally and physically traumatised due to the Troubles; and

- people involved in substance abuse/dual diagnosis.

5.184 It is beyond the remit of this Review and this Report to address all the above in a totally comprehensive fashion. The Review, however, has attempted to highlight important current issues, identify some examples of evidence based good practice, and highlight some practical, locally sensitive key issues to be addressed which include, where appropriate, reference to the existing Strategy and Action Plan 03-08.

5.185 The Strategic Framework for Adult Mental Health Services addresses clinical aspects of care and treatment in some depth with a vision of a "whole system of care" (p. 79) with an emphasis on recovery models.

5.186 This Report aims to highlight some examples of preventative good practice, at primary, secondary and tertiary levels.

PEOPLE WITH ENDURING MENTAL ILLNESS

The Case for Action

5.187 In discussing the issues surrounding mental health promotion for people with enduring mental illness, the debate about prevention in relation to mental health promotion inevitably comes into play.

5.188 Traditional public health definitions of prevention (Caplan 1964) are:

- **Primary Prevention** - involves efforts directed at reducing the incidence in the community. Primary prevention efforts are directed at people who are essentially "normal", but believed to be at risk from the development of particular disorders.
- **Secondary Prevention** - involves efforts to reduce the prevalence of the disorder by reducing its duration. The goal is to shorten the duration of the disorder by early and prompt treatment.
- **Tertiary Prevention** - is designed to reduce the severity of disability associated with a particular disorder.

5.189 Recently it has been shown by a body of evidence that mental health promotion can contribute to the prevention of certain disorders, eg. anxiety , depression and substance abuse. It can also contribute to the health improvement for people whether or not they are at risk of mental illness as well as for people with mental health problems (Mental Health Foundation 2000).

What Works?

5.190 **School-Based Programmes** - universal protective factors among populations has been found to reduce depressive symptomatology. Examples include school-based programmes targeting cognitive, problem-solving and social skills of children and adolescents and exercise programmes for elderly people.

5.191 Some of these programmes such as the RAP in Australia found reductions in high depressive symptom levels of 50% or more one year after the intervention (Schochet et al 2001).

5.192 **Parenting Skills** - parenting interventions for parents of children with conduct problems aimed at improving parental psychological well-being by information provisions and by training in behavioural childrearing strategies have shown reduction in parental depressive symptoms of about 30% with improvements in children's outcome.

What Works?

5.193 **Specific Mental Health Disorders** - as there is a necessity to be selective for the purposes of this Report we have chosen to explore the issues for the 2 potentially psychotic disorders affective disorders, whether unipolar or bipolar, and schizophrenia.

5.194 **Schizophrenia - Early Intervention** - it seems that early drug treatment of schizophrenic episodes may improve the prognosis. Indications are that a delay in initiating of treatment leads to poorer long term outcomes; that persistence of symptoms untreated by neuroleptic drugs leads to abnormality which cannot be completely reversed by subsequent treatment.

5.195 **Affective Disorders - Education for Primary Care Professionals** - affective disorders are essentially a community problem: only one per 1,000 of the population are admitted to hospital annually in England because of severe illness (Bebbington 1978).

5.196 However, approximately 3% are seen annually by GPs with recognised depression with about an equal number unrecognised and a community 6 month prevalence of 3-5% (Smith & Weissman 1992).

5.197 In Sweden, Rorsman et al (1990) described a programme that improved detection and management of depression. Evidence from England (Gask et al 2000) suggests that an educational package aimed at improving the interviewing skills of primary care physicians produces similar results.

Opportunities for Employment

5.198 **Supported Employment** - supported employment within a normal working environment is more effective in improving employment prospects for people with long-term mental health problems than sheltered workshops or pre-vocational training (Crowther et al 2000).

What Works?

5.199 **Social Skills Training (SST)** - one of the main assumptions underlying social skills training is that people with schizophrenia have either not learned, or have forgotten, the behaviours necessary for successful social interaction and interpersonal relationships (Halford & Hayes 1992).

5.200 A typical social skills approach is to set up an educational class with 1 or 2 trainers and 5-10 patients as students.

5.201 Studies reviewing SST for people with schizophrenia conclude that SST is effective in increasing patients' ability, comfort and assertiveness in social situations (Birchwood & Spencer 1999).

5.202 **Sheltered Housing** - a range of agencies in Northern Ireland, both statutory and voluntary, provide sheltered accommodation in the community for those with enduring mental health needs. The ethos may vary from organisation to organisation, but most seek to empower the individual and promote maximum independence within a supported setting. Helping to increase individuals' social networks and opportunities for involvement in the local community are core factors.

The Key Issues to be Addressed

5.203 The Strategic Framework for Adult Mental Health Services has recommended a strategic framework for the provision of services in this area. However, in terms of mental health promotion, there is now a body of evidence to show that this can contribute to the prevention of certain disorders, such as anxiety, depression and substance abuse. It can also contribute to the health improvement of people whether they are at risk of mental illness as well as for those with mental health problems.

- An educational programme in Sweden improved the detection and management of depression. Evidence in England suggests that an educational package aimed at improving the interviewing skills of primary care physicians produced the same results.

5.204 It is suggested that this training could be applied here in a primary care setting, with all primary care professionals.

PEOPLE WITH EATING DISORDERS

The Case for Action

5.205
- In Northern Ireland, approximately 50-120 people develop anorexia nervosa per year, and 170 develop bulimia nervosa. As not all sufferers seek treatment, it is often difficult to assess the full scale of the problem, however, it is estimated that approximately 340-1,700 have suffered from anorexia, with 1,700 suffering from bulimia.

- Around 100 people are admitted to hospital each year in Northern Ireland with an eating disorder.

- About 50% of patients with anorexia recover, 30% make a partial recovery and 20% remain anorexic. Bulimia shows a recovery rate of 2 out of 3 over a 5 year period. Treatment is most effective when provided early (DHSSPS 2002).

- The DHSSPS 2002 Consultation paper on Eating Disorders states that a paper by the RCP recently described services here as “woefully inadequate”.

What Works?

Examples of Good Practice in the Prevention of Eating Disorders

5.206 **Life Skills Training Programmes** - life skills training have been included in a number of eating disorder prevention programmes. A review of these programmes (Levine et al 1999) reported that 85% of the programmes that included a life skills training component was effective compared with a 56% effective rate amongst those programmes that did not include such a component.

Eating Disorders in an Educational Setting

The Eating Disorders Project, Gloucestershire

5.207 Attempts to prevent the development of eating disorders within schools have been shown to be ineffective (Fairburn 1995). However, recent studies have shown that a multi-dimensional approach has better outcomes. In some studies preventive effects have been found for eating related attitudes, interpretation or acceptance of societal ideals of appearance, feelings of ineffectiveness, body dissatisfaction and dietary behaviour.

Body Image

5.208 The Everybody's Different Programme in Australia which focused on improving self-esteem was effective in reducing body dissatisfaction in young people and altering weight control behaviour in girls (O'Dea & Abraham 1999).

5.209 This programme showed that even 12 months after the programme participants showed improved body satisfaction, more positive self-esteem, social acceptance, and low drive for thinness.

The Key Issues to be Addressed

5.210
- Examples of good practice in terms of prevention indicate that the key issues to be addressed include: life skills training programmes and programmes which focus on improving self-image and reducing body dissatisfaction in young people.
- Given that early recognition means that treatment is most effective, in terms of mental health promotion, programmes should focus on early intervention.

PEOPLE AT RISK OF SUICIDE

The Case for Action

5.211 There has been a dramatic increase in the number of young people taking their own lives. Within Northern Ireland, suicide now exceeds road traffic accidents (RTAs) as a cause of death, with 163 dying by suicide and 129 dying by RTAs in 2000. According to statistics from the General Registrar's Office, 2001, suicide is the number one cause of death in people aged between 15-34 years and the rise is particularly concerning amongst young males.

What Works?

5.212 There are a number of strategies in place in Northern Ireland. The Western Health and Social Services Board (WHSSB) Suicide Prevention Strategy (1996) represents the Board's firm commitment to tackle suicide and provides a context for a multi-agency approach to tackling suicide among the resident population.

5.213 The WHSSB Suicide Strategy, based on WHO guidelines for suicide prevention, consists of 4 key elements:

- **Education -** of the public through campaigns; education of professionals in the statutory, community and voluntary sectors; and education in schools and colleges.
- **Environment -** reducing access to the means of suicide such as the introduction of paracetamol legislation (Hawton, 2002).

- **Media -** working with the media to recognise the protective role sensitive reporting can have, eg. producing media guidelines.

- **Research -** recognising the importance of co-ordinating research programmes in order to avoid overlap or duplication of research projects.

5.214 Since the implementation of the WHSSB Suicide Strategy significant progress has been made in developing a range of programmes in all of the 4 key areas. These programmes have been the outcome of the successful collaboration of the members of the Foyle and Sperrin Lakeland local fora on Suicide Prevention supported by the SuicideAwareness Co-Ordinators.

5.215 North and West Belfast HSS Trust has shown similar innovation by appointing a Suicide Awareness Co-Ordinator, who has been instrumental in implementing many initiatives.

5.216 Ten specific action points have been identified in the Strategy andAction Plan 03-08 under the preventing suicide section. Much has been achieved at local level to ensure these action points have been realised, however, someone needs to take regional responsibility to ensure consistency across Northern Ireland.

Public Awareness

5.217 It is important to provide information to the public about major health issues including mental health and suicide. As suicide may be seen as an extreme result of poor mental health, then it is important that the public are informed about the possible signs of depression and other forms of mental illness and the sources of help.

5.218 Research would indicate that a better -informed public is more likely to access services at an earlier date. Action 13 of the Strategy and Action Plan 03-08 recognises the need for a public and professional information campaign, however , if this is to happen it should be properly resourced similar to R TA campaigns. Action 14 of the Strategy and Action Plan 03-08 states that *“All HSS Boards have taken action to ensure that information about local sources of help on mental health issues is available and accessible.”*

5.219 Examples include the design and production, in consultation with young people, of a flyer and poster and development of the “Heads Away Campaign” by North and West Belfast HSS Trust and health promotion leaflets on depression and suicide.

ASIST (Applied Suicide Intervention Skills Training)

5.220 In line with Action 25 funding was obtained from the DHSSPS Health Promotion Branch, to bring Living Works Incorporated, Canada to Northern Ireland to deliver the Training for Trainers Course on ASIST. This course is available worldwide and has been adopted as the standardised training programme in Canada, Australia, Norway, and many of the States of

American and the US Army and Air Force and is now being delivered throughout Northern Ireland. A similar approach and commitment, as that adopted for the ASIST Programme, is required for each of the other 29 action points of the Strategy and Action Plan 03-08.

The Key Issues to be Addressed

5.221 • Any new Suicide Strategy needs to be cognizant of the UN/WHO guidelines and Safety First recommendations and needs to draw on good practice in the rest of the UK and the Republic of Ireland. It is imperative that in order for it to be implemented it needs to be resourced with an identified action plan with target dates, identified responsibilities, etc.

5.222 The Multi-Sectoral Task Force engaged with a wide number of individuals and organisations in drafting the document, Protect Life - A Shared Vision 2006-2011.

5.223 This document identified specific actions with a targeted approach, eg. looking at the needs of those who self-harm; people with a mental illness; young males; marginalised and disadvantaged groups; and people who have been bereaved by suicide.

5.224 Detailed recommendations on suicide prevention are in Annex 2.

PEOPLE EMOTIONALLY AND PSYCHOLOGICALLY TRAUMATISED DUE TO THE NORTHERN IRELAND "TROUBLES"

The Case for Action

5.225 Since the Troubles began in Northern Ireland 3,600 people have been killed and 40,000 injured. This is within a population of 1.5 million. Whilst most researchers now agree that the Troubles have had an effect on the health and well-being of our community, the extent of their impact on mental health has been disputed and under estimated for a number of reasons (Duffy 2004).

5.226 The DHSSPS Report of 1998, "Living with the Trauma of the Troubles" has an impressive list of recommendations for action, including:

- the development of crisis support teams;
- a proper review of the appropriateness and quality of counselling services for people affected by the Troubles;
- services to be registered;
- information to be made available by all Trusts and via other agencies; and
- better co-ordination of services.

5.227 The Bloomfield Report "We Will Remember Them" (1998) took a 2 strand approach; practical help such as criminal injuries compensation; a non-physical memorial scheme and a physical memorial scheme. The Bloomfield Report lists 20 recommendations on a range of issues. Two have a particular mental health promotion slant:

- **Recommendation b -** employers should be sensitive to the special circumstances of victims and their carers, and specific actions should be taken by public sector employers to assure this; and

- **Recommendation p -** consideration should be given to the creation of a fund to assist in particular children and young people affected by the deaths or injury of a parent.

5.228 Wars and serious societal conflict such as the Troubles have a severe impact on post-war societies. They tend to lead to the breakdown of infrastructures, loss of social capital and lead to major risk factors in terms of psychotic morbidity and suicide.

What Works?

5.229 Please refer to A Strategic Framework for Adult Mental Health Services (June 2005) Section 6.29, pp 116-119.

Local and International Examples of Good Practice

Social Capital – Individuals, Organisations and Communities Under Stress Post Conflict

5.230 Recent research on social capital and inequality suggest that how individuals and communities feel - lack of trust, tolerance and participation - may be a critical factor in determining health (Wilkinson 1996 & 2000). The impact of the Troubles, such as residential segregation, population movement and displacement, stigmatisation of certain neighbourhoods, bereavement and trauma is acknowledged in the Strategy andAction Plan 03-08. Action 5 refers specifically to the promotion of mental health with vulnerable groups such as victims of the conflict.

- It is recommended by WHO, that preventive efforts to reduce the onset of mental disorders (such as anxiety, depression and PTSD) in post conflict societies should focus primarily at early interventions after trauma, rebuilding the country's physical and mental health services and social infrastructures, mental health education and offering emotional, societal and economic support to victims (WHO 2004).

- Cognitive Behavioural Therapy (CBT) as a treatment for Post Traumatic Stress Disorder (PTSD) has been shown to be effective through the work of the Northern Ireland Trauma and Transformation Centre.

- Family therapy approaches in North and West Belfast HSS Trust have also reported positive individual and family effects following therapy and treatment.

Key Issues to be Addressed

5.231
- Over and above actual treatment, additional resources should be provided for day to day support and training of those who help people in the community affected by the conflict, and to help enhance social capital.
- Consistent with WHO recommendations for post-conflict societies, preventive initiatives are required to reduce the onset of mental disorders such as anxiety, depression and PTSD focusing primarily on early interventions after trauma, rebuilding our community's physical and mental health services and social infrastructures, mental health education and offering emotional, societal and economic support to victims (WHO 2004).
- The development and expansion of evidence-based services, including Clinical Resources Efficiency Support Team (CREST) guidelines, to address psychological trauma and including adult survivors of childhood trauma should be taken forward as a priority.

PEOPLE INVOLVED IN SUBSTANCE ABUSE/DUAL DIAGNOSIS

The Case for Action

5.232 Chapter 4 of the Strategic Framework for Adult Mental Health Services Report deals with the issue of people with severe mental disorder and substance misuse (dual diagnosis). Those with a dual diagnosis can "fall between two stools" with mental health and addiction services accepting responsibility for their treatment needs. The Report gives recommendations for different treatment approaches.

5.233 **Substance Related Disorders** - the prevention of mental and behavioural disorders due to psychoactive substance use includes the prevention of acute intoxication, harmful use and dependence. The term "psychoactive substances" encompasses tobacco, alcohol and illicit drugs (eg. opioids, cannabinoids and cocaine), as well as psychoactive prescriptions drugs and solvents. Globally, tobacco as a risk factor causes 4.1% of the total burden of disability (WHO 2002). In the 21st Century, it is estimated that tobacco will be the cause of one billion deaths worldwide, with three quarters of these death occurring in low income countries. Worldwide, about 2 billion people consume alcoholic beverages and over 75 million are diagnosed with alcohol use disorders (WHO 2004). Alcohol as a risk factor causes 4% of the total burden of disability (WHO 2002).

5.234 Given the particular concern about binge drinking, especially in the young, and the limits of this Report in terms of scope, the focus in this section is on alcohol abuse.

Northern Ireland

What Works?

5.235 Dr Diana Patterson, Consultant Psychiatrist at the Shaftesbury Square Hospital, Belfast and Convenor of the Review's Alcohol and Substance Misuse Expert Working Committee responded to our request for views on mental health promotion and substance abuse as follows:

Adult Services – within the broad areas of alcohol misuse it has been accepted for many years that there is significant improvement in morbidity and mortality when population wide interventions are employed. Interventions which affect the price (or relative price) of alcohol to the consumer are those which are likely to have the greatest beneficial health effect on our population. Others, targeted at reducing the overall volume of alcohol consumed by our population can be shown to have dramatic effects on morbidity and mortality from alcohol misuse. Other more directly targeted interventions such as screening and "early interventions" have been shown to be efficacious and may properly be considered as part of health promotion, rather than considered as individual direct interventions. As these early interventions now form a major part of the importance within the field of health promotion.

Young People's Services - with regard to this group, even greater emphasis must be placed on health education and its preventive role. The future adults of our society have a right to education about alcohol and drugs so that they can make informed choices about these substances.

What Works?

5.236 **Selective and Indicated Interventions –** brief interventions are highly effective as well as cost-effective for reducing hazardous and harmful alcohol consumption. Brief advice from a GP routinely given to all patients who smoke and drink leads to about 40% attempting to stop and about 5% stopping for at least 6 months (a strong predictor of permanent success) (Lancaster & Stead 2004).

5.237 **Community Interventions –** community mobilisation has been used to raise awareness of problems associated with on-premises drinking, develop specific solutions to problems and pressure bar owners to recognise that they have a responsibility to the community in terms of bar-related issues, such as noise level and patron behaviour. Evaluation suggests that community mobilisation can be successful at reducing aggression and other problems related to drinking in licensed premises. For example, a comprehensive, locally designed intervention under the Saving Lives Project, including media campaigns, business information programmes, speeding and drunk driving awareness days, speed watch telephone hotlines, police training, high school peer-led education, college prevention programmes and other activities, led to a 25% decline in fatal crashes, a 47% reduction in the number of fatally injured drivers who were positive for alcohol, a 5% decline in visible crash injuries and an 8% decline in crash injuries affecting those aged 16-25 years (Hingson et al 1996).

5.238 There are some relevant examples of good practice in Northern Ireland. The Drug and Alcohol Strategy Team, through its encouragement of interdepartmental Government structures, has influenced the Department of Education in Northern Ireland to provide a comprehensive education package which is now available to all school children for their appropriate ages through the mainstream education process. Within this process, alcohol and drugs education is delivered through a larger health promotion programme and is not designed as a "stand-alone" piece of education.

Risk Taking Behaviour

5.239 Brief interventions in primary care are effective in reducing alcohol consumption in heavy drinkers (Wilk et al 1997).

Reducing Alcohol Consumption

5.240 There is a strong case for taking an alcohol history , followed by brief interventions in Accident and Emergency Departments, using an approach developed at St Mary's Hospital NHS Trust in Paddington, London. Over half the men who present to hospital after deliberate self-harm regularly drink excessive amounts of alcohol and 23% are alcohol dependent.

Key Issues to be Addressed

5.241 Both the Strategic Framework for Adult Mental Health Services and the Alcohol and Substance Misuse Report, December 2005 deal with the issues relating to people who have developed alcohol or drug problems:

- Availability of alcohol is a factor and, therefore, there may be political aspects to dealing with the problem away from excess drinking. Politicians should be lobbied in this regard.

- The HPA could have a significant role in developing a strategy province-wide to help promote healthier drinking, drawing on examples of good practice and research nationally and internationally.

CHAPTER 6

POLICY ISSUES

The Policy Environment

Introduction

6.1 The importance of mental health promotion and its contribution to overall health has achieved growing recognition across the UK and Internationally (Jenkins 2002; WHO 2005; Jané-Llopis & Anderson 2005).

National Policies

6.2 England, Scotland, Wales and Northern Ireland all have policies with a specific mental health promotion focus and have all in recent years developed strategies for the delivery of mental health promotion.

Northern Ireland

6.3 In Northern Ireland, the overall policy environment is currently considered relatively favourable to promoting mental health and stimulating a wide range of activity . PSI is a key element of New Targeting Social Need, (Northern Ireland Office 2003) which has a special focus on mental health. Promoting mental health and well-being at an individual and community level is one of the objectives of Investing for Health, the regional health strategy for Northern Ireland launched in 2002.

6.4 The Strategy and Action Plan 03-08 was published by the DHSSPS in January 2003, following responses to the consultation document "Minding Our Health" (2000). In addition, responses to the wider Investing for Health consultation highlighted mental health as a key priority for action (DHSSPS 2002).

6.5 The Strategy and Action Plan 03-08 aims to improve mental and emotional well-being and to prevent or reduce the impact of mental illness. In addition, it has two aims concerned with the determinants of mental health at a policy level and building capacity and skills for effective mental health promotion practice. Overall, it strikes a balance between addressing life circumstances and developing life skills and is based on three principles: a holistic approach; empowerment; and respect for personal dignity . The Strategy and Action Plan 03-08 addresses four areas: policy development; raising awareness and reducing discrimination; improving knowledge and skills and preventing suicide.

6.6 Overall monitoring of the Strategy and Action Plan 03-08 is the responsibility of the Ministerial Group on Public Health, with a DHSSPS led Multi-Agency Group overseeing the action plan. Each of the four Health and Social Services Boards across Northern Ireland is required to develop local mental health promotion strategies. The WHSSB was the first to launch its plan at a major consultation event in Strabane in November 2003. A similar launch by the Southern Health and Social Services Board (SHSSB) took place in January 2004. Within the WHSSB, delivery of the suicide prevention element of the strategy is overseen by two suicide awareness co-ordinators, with a strong focus on both public and professional education, working with the media and an extensive programme in schools and prisons.

Response to Promoting Mental Health – Strategy and Action Plan 2003-2008

6.7 The Strategy and Action Plan 03-08 has been widely welcomed by people in the mental health field in Northern Ireland and represents an important milestone in putting mental health promotion on the health agenda. In addition, involvement by a range of agencies, statutory, community and voluntary, has meant a collaborative approach to mental health promotion which has been beneficial. Nevertheless, feedback outlined below suggests that there are some concerns about the impact of the strategy.

Implementation – Progress to Date

6.8 The HP A in Northern Ireland was charged with the task of taking forward an implementation group to monitor progress with the 30 stated actions Ultimately the Implementation Group will report to the Ministerial Group on Public Health (currently under review).

6.9 In addition to Implementation Group meetings which have been held, 2 sub groups have recently been established to look in further detail at (a) suicide prevention and (b) education. These consultation groups have been set up with the aim of engaging with local stakeholders to help assess progress to date in terms of the actions relating to these 2 areas. Suicide is now the subject of a separate Government report, Protect Life -A Shared Vision, 2006-2011.

6.10 As part of its own consultation, the Mental Health Promotion Committee designed a questionnaire for key stakeholders provide-wide, seeking feedback on issues relating to mental health promotion generally and more specifically seeking comment on the current strategy and perceived progress to date. Outlined below is a summary of feedback received from this, one of whose questions asked for comment on the strategy and perceived progress.

6.11 Fifty questionnaires were completed by a diverse range of agencies and individuals from the statutory, voluntary and community sectors. In addition to the questionnaire, views from members of the Committee and from other individuals working in the statutory and community sectors have been sought on a one-to-one basis.

6.12 Support for the Strategy and Action Plan 03-08 was clear, with a number of agencies involved in taking forward some of the actions outlined. However, respondents of the questionnaire and others commenting expressed concerns as following:

- **Unrealistic Timeframes -** a number of the target dates for completion of action had already passed by the time the document was disseminated.

- **The Need for Guidance -** quite a number of those commenting on the Strategy have highlighted the lack of guidance (such as DOH's Making It Happen – a Guide to Delivering Mental Health Promotion (2001) – published to assist with the implementation of the National Services Framework Standard on mental health promotion in England).

- **Inadequate Resources -** approximately £200,000 is earmarked for mental health promotion in Northern Ireland. This is currently allocated to the HSS Boards to help them resource local board initiatives. This is considered to be woefully inadequate, particularly in the light of the higher incidence of mental health problems in Northern Ireland compared to the rest of the UK.

- **Targeting Resources -** given that many of the actions do not simply involve the health sector, consideraion would need to be given to resourcing education, district councils, community organisations, prison service, etc.

- The Scottish National Programme for Mental Health Promotion, with an allocation of £24 million represents a major investment and commitment. On a pro rata basis, the Committee believes that £5-6 million would be required to develop the infrastructure of the proposed Mental Health Promotion Directorate in the Northern Ireland. This level of resourcing would facilitate funding streams to be developed from other sectors such as education and employment.

- **Reinforcing of Cross-Sectoral Collaboration -** although a number of the actions (eg. Action 15 & 14) have an expectation of, for example, HSS Boards and HSS Trusts and Education and Library Boards working together , there seems little evidence that this is happening, except at local level.

  The Health Promoting School is one example of an initiative in an education setting being driven forward by the Department of Health solely in terms of funding with the HPA progressing the action.

- **The Need for Ministerial Direction -** there is a need for clear direction at the most senior level to drive the strategy forward (as in the Scottish Executive Model) - someone who can call people to account.

- **Question of Mainstreaming/Sustainability -** it is at present unclear what will happen beyond 2008. The issue of short-term interventions with lack of resources to mainstream successful initiatives has long been a feature of mental health promotion in Northern Ireland.

- **Representation on the Implementation Group -** members of the group should be in a position to influence the policy-makers and properly oversee relevant actions.

- **Gaps in the Strategy/Lack of Specificity -** a number of gaps have been identified in terms of vulnerable groups such as:
  - victims of domestic violence;
  - people with a learning disability;
  - needs of people with ASD;
  - ethnic minorities; and
  - specific at risk groups, eg. children, elderly and the isolated.

- **Gaps in the Consultation Process -** some respondents commented on their lack of consultation as follows:
  - midwives;
  - occupational therapists;
  - student population;
  - users of services.

- **Research** - further research into assessment of need is required.

National Service Framework for Mental Health - England

6.13 In 2001, the DOH developed a revised performance management framework to monitor progress on the implementation of all National Service Framework (NSF) standards and the NHS Plan as it relates to mental health.

6.14 The NSF Standard One on mental health promotion meant that a clear remit for the first time had been given to health and social services to promote mental health for all and to reduce the discrimination experienced by people with mental health problems. Recently , the importance of Standard One has been reinforced in the public health White Paper, “Choosing Health”, which includes a specific commitment to new services to improve the mental and emotional well-being of the whole population and states:

“*we will ensure that standard one of the NSF for Mental Health, which deals with mental health promotion, is fully implemented.*” (Department of Health 2004a)

6.15 The importance of mental health promotion is also recognised in the NSF Progress Report by the National Director for Mental Health “The National Service Framework for Mental Health: Five Years On”, which notes:

“we *need to broaden our focus from specialist mental health services to the mental health needs of the community as a whole*.” (Department of Health 2004b)

6.16 In England to date, the main focus nationally has been on tackling discrimination and social exclusion, notably with the publication of “Mental Health and Social Exclusion” by the Social Exclusion Unit (SEU) (2004) and NIMHE’ s strategy “From Here to Equality” (NIMHE 2004). Guidance on developing local mental health promotion strategies:

"Making it Happen", was published in 2001 (DOH) and by the end of 2004, 91% of primary care Trusts had met the requirement to have a mental health promotion strategy, although resources for mental health promotion delivery vary widely and are generally very limited. There are some indications that this might improve with the impetus provided by "Choosing Health" (DOH 2004a) and the fact that NIMHE has recently commissioned a National Framework for Mental Health Promotion in England, to inform the further development and delivery of mental health promotion.

6.17 **Lessons -** England has been successful in putting the exclusion and discrimination experienced by people who use mental health services high on the agenda; if implemented, the recommendations in the SEU's Report are likely to make a significant difference to the quality of life of people with severe and enduring mental health problems. However, there is still a need for a greater focus on promoting mental health for all and moving mental health promotion higher up the public health agenda.

Mental Health in Scotland – A National Programme Approach

6.18 In 2000, the Scottish Executive outlined a commitment to mental health as an integral part of the wider agenda for public health and health improvement in Scotland (Scottish Executive 2000). As a result, in October 2001, the Scottish Executive unveiled a new programme for improving mental health and well-being (Henderson et al 2002). Resources to the value of £24 million have been dedicated to this programme - the first of its kind in Scotland, where national policy and resources have been dedicated to improving mental health.

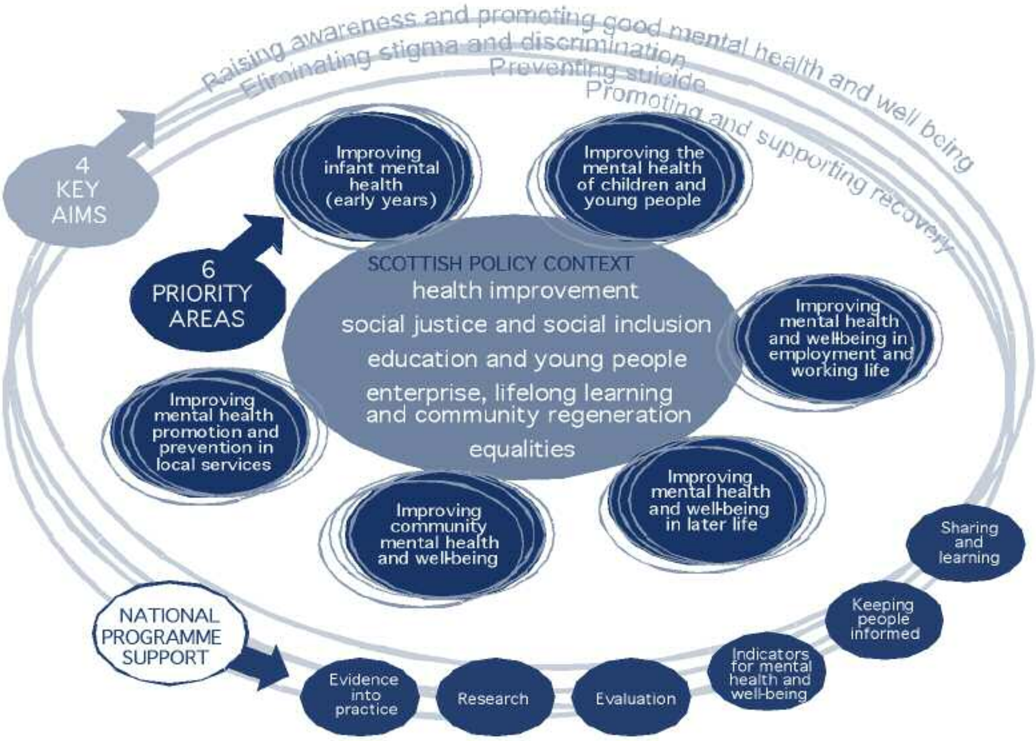
6.19 Commitment from the top (always a predictor of success) is manifested by the consultation and support body - the National Advisory Group, chaired by the Deputy Minister for Health and Community Care, which advises Scottish Ministers on the programmes, strategic direction and implementation.

6.20 There is wide representation on the group – including those who work in health, education, housing, local authorities, employment, learning and justice.

6.21 The Scottish National Programme Action Plan (see below) was published in September 2003, setting priorities for actions such as:

- raising awareness and promoting good mental health and well-being;
- eliminating stigma and discrimination;
- preventing suicide; and
- promoting and supporting recovery.

The Scottish National Programme Action Plan – Graphical Representation



6.22 This is supported by a range of activities including collecting and disseminating the evidence base and supporting local practice, developing and commissioning a programme of national research and establishing public health indicators.

6.23 The strength and profile of the Scottish National Programme for Improving Mental Health and Well-Being (www.wellontheweb.net) means that the environment in Scotland is widely seen as extremely favourable to mental health promotion. In addition to a high profile media campaign and a wide range of activities to promote mental health and address discrimination, suicide and recovery , Scotland has seen a major investment in building capacity for the delivery of public mental health. This has included a range of training, research and resources commissioned by the Scottish Executive and NHS Health Scotland. A further major programme of mental health improvement training, with a focus on evidence into practice, is scheduled for 2005/2006, with events across all Scottish Health Boards (contact Scottish Development Centre for Mental Health www.sdcmh.org.uk).

6.24 **Lessons -** in addition to specific action on stigma and discrimination, it is also crucial to create an environment which promotes the mental health of the whole community - in schools, in workplaces, in neighbourhoods, in primary care, in local Government, the voluntary and private sector. This cannot be achieved without dedicated resources to build knowledge, skills, expertise and capacity.

6.25 This innovative and progressive approach is a model to be admired. One of the important factors is that, although the funding comes to an end at the end of 2006, the National Programme seeks to embed itself in Scottish policy and practice before that, leading to a long term commitment.

6.26 In a journal article recently published, Research Specialist, Emma Hogg, states that:

"The work programme described should help to secure lasting commitment to mental health improvement and contribute to the shift from a focus on treatment issues to a more equal balance between treatment and promotion and prevention". (Hogg, 2004)

6.27 For information on progress to date of the work of the National Programme, see Annex 5.

International Policy

6.28 A resolution passed by the Council of the European Union in November 1999, calls on the European Commission to recognise the importance of promoting mental health and to assess the mental health impact of policy.

6.29 The resolution invites the members to:

- develop mental health promotion policies;
- collect and share relevant data;
- implement action to promote mental health and prevent mental illness; and
- stimulate research into mental health and its promotion.

6.30 It calls on the European Commission to:

- incorporate mental health into the public health programme;
- monitor mental health as a component of the community health monitoring system;
- analyse the impact of community activities on mental health; and
- consider drawing up a recommendation on the promotion of mental health.

6.31 Also relevant to mental health promotion are the European Convention of Human Rights and the Human Rights Act 1998.

6.32 Although many countries have started to recognise that mental health policy to enhance public mental health has significant potential in terms of improving economic, social and human capital, Lahtinen et al (1999) in their analysis of the position of mental health in Europe have argued that mental health has not achieved equal recognition with physical health among decision-makers.

WHO Ministerial Conference on Mental Health

6.33 This Conference brought together all 52 countries in the European Region of the WHO. Organised in partnership with the European Union and the Council of Europe. Arising from this conference was the “Mental Health Action Plan for Europe Facing the Challenges, Building Solutions 2005”.

6.34 The WHO Action Plan (2005) was endorsed in the Mental Health Declaration for Europe by Ministers of Health of member states in the WHO European Region.

6.35 It also sets out the details of commitments and responsibilities of both the WHO and national governments. It has 12 priority areas, with a strong public mental health focus, including:

1. Promote mental well-being for all.
2. Demonstrate the centrality of mental health.
3. Tackle stigma and discrimination.
4. Promote activities sensitive to vulnerable life stages.
5. Prevent mental health problems and suicide.
6. Ensure access to good primary care for mental health problems.
7. Offer effective care in community-based services for people with severe mental health problems.
8. Establish partnerships across sectors.
9. Create a sufficient and competent workforce.
10 Establish good mental health information.
11. Provide fair and adequate funding.
12. Evaluate effectiveness and generate new evidence.

6.36 It stresses the need for *“mental health activities capable of improving the well-being of the whole population, preventing mental health problems and enhancing the inclusion and functioning of people experiencing mental health problems.”* Of special note is the emphasis on increasing awareness of the importance of mental well-being, the inclusion of promotion and prevention (alongside the need to improve treatment and services) and the recognition of the need for a competent workforce in all these areas.

Summary

6.37 Regionally, the Strategy and Action Plan 03-08 is welcomed. Its ethos, underpinning values and actions are all highly appropriate. It also helps to reinforce much good practice in the field of Mental Health Promotion over the years (much of which is captured in HPA's Database) and is, therefore, encouraging to those who believe there must be a positive impetus for the future. However, as outlined above, many of the strategy recommendations have not been implemented.

6.38 The hard reality of the cost benefits of taking action – a projected £30 billion savings by 2022 cited in the NHS Improvement Plan, may well be an incentive for action, in addition to the cost to Northern Ireland economy of mental ill health of £2.28 billion, as outlined in Chapter 3.

6.39 Whether the reasons are "hard" or humanistic, or a combination of both, the priority is to progress towards mental health for all.

CHAPTER 7

RECOMMENDATIONS

Primary Recommendation:

The Creation of a Regional Mental Health Promotion Directorate at the Heart of Government

7.1 The stated vision of this Report is "mental health for all". As WHO (2005) states: *"There is no health without mental health"*. As the title of this Report reflects, mental health promotion needs to have the following dimensions: personal; public; and political.

7.2 **Personal** – early prevention and the enhancement of individual mental health and well-being helps promote social inclusion, autonomy, resilience and the capacity to learn, develop and contribute meaningfully to society.

7.3 **Public** – environmental factors such as feeling safe, access to appropriate local support, education, opportunities for employment and meaningful activity all need to be generated by good cross sectoral working particularly by the health, education and employment agencies.

7.4 **Political –** in the current climate of scarce resources, it may take a political "leap of faith" by policy-makers. Resource allocators in all sectors need to be convinced of the fact that good mental health is the starting point for all health. The current WHO Action Plan 2005 reinforces these points in terms of European Policy. This needs to be translated into regional terms in Northern Ireland.

7.5 In light of the above, the Review believes that in order to achieve strategic, co-ordinated, cross-sectoral, cross-departmental and multi-agency action on mental health promotion, a Regional Mental Health Promotion Directorate, with a Regional Director should be established.

7.6 A properly resourced Directorate would increase awareness and visibility of mental health promotion, facilitate the achievement of existing mental health promotion targets, as well as setting targets for the future. This would provide a necessary degree of permanence, leadership and sustainability to drive forward mental health promotion in Northern Ireland.

7.7 The costs of mental-ill health are felt across a wide range of public sectors. Effective responses, therefore, require a multi-agency approach. Joined-up Government is notoriously difficult to achieve in practise. A Regional Mental Health Promotion Directorate would, therefore, have the task of promoting this multi-agency approach with a shared ownership and a mental health promotion vision.

7.8 The establishment of such a body, with proper executive powers is, to a large extent, predicated on the fact that, although excellent in content, the current Strategy and Action

Plan 03-08 is not having the impact it should. Some of the barriers to its effective implementation have been outlined in Chapter 6, and include inadequate resources; lack of ministerial direction; lack of guidance, authority and accountability to promote cross sectoral collaboration, and importantly, lack of co-ordination.

7.9 The Review, having agreed and recommended this Directorate as necessary for providing strategic, co-ordinated, cross-sectoral, cross-departmental and multi-agency action on mental health promotion, then considered the appropriate structures and siting to achieve this function.

7.10 The Review considered where the centre of gravity should be for this recommendation. Should it be focused within the health sphere or if, as we are, looking to wider contributions, including those of education, culture and employment to produce the change we want, what mechanism and approach is most effective in making those linkages?

7.11 The Review considers that it is necessary, in order to achieve this strategic vision, to place a Mental Health Promotion Directorate at the heart of Government. The Review's recommendation is to ensure mental health promotion is a policy priority across the whole of the public sector. To achieve this, the Directorate would best be placed within a context such as OFMDFM.

7.12 A properly resourced Directorate would increase awareness and visibility of mental health promotion, facilitate the achievement of existing mental health promotion targets, as well as setting targets for the future. This would provide a necessary degree of permanence, leadership, sustainability and crucially the authority to drive forward mental health promotion in Northern Ireland whilst creating ownership of mental health promotion across all sectors and relevant agencies and groups.

7.13 The challenges for the next 10-15 years as outlined in WHO Action Plan 2005 can only be addressed through such a body, established with the authority that would be forthcoming within a context such as OFMDFM.

7.14 This would enable proper co-ordination of any mental health promotion strategies, identified directions for the future, and through the promotion of cross-sectoral responsibility enhance the understanding and development of social capital in relation to mental health promotion.

Key Functions and Responsibilities of the Directorate

7.15 A Mental Health Promotion Directorate at the heart of Government would ensure that mental health promotion contributes to the goals and policies across all sectors, supports the delivery of existing policies relevant to mental health promotion, raises the awareness of mental health promotion and moves mental health promotion up the policy agenda in all Government Departments and agencies.

7.16 In particular, taking account of the recent Review of PublicAdministration (RPA 2005), the Review would see this Directorate as ensuring that the HPSS Authority and the New Education Authority take on the responsibility for operationalising the impact of this policy in those two most important sectors.

7.17 Specifically the functions may include the responsibility to:

- co-ordinate the implementation of existing policies, including the Strategy and Action Plan 03-08;
- facilitate the necessary cross-sectoral approach to mental health promotion by providing a focus for liaison between the various governmental bodies;
- facilitate capacity building via training and research with regard to mental health promotion across all health, social care and education professions, with a particular focus initially on primary care level;
- facilitate the establishment of a research body providing a focus on mental health as opposed to mental illness, specialising in non clinical domains; providing an information base and guidance; and identifying examples of good practice; quality assurance approaches and independent evaluation on public mental health promotion strategies and interventions;
- ensure that there is a focus on relevant legislation regarding equality of opportunity and human rights as regards to mental health;
- identify priorities in terms of the population, vulnerable groups, etc;
- liaise with other UK and International Programmes;
- ensure the permanence of mental health promotion, by embedding it in all public sector policies, especially health and education; and
- implement effective responses.

Other Recommendations

7.18 The Review considers the creation of a Mental Health Promotion Directorate at the heart of Government as its primary recommendation upon which action on mental health promotion would be based across Northern Ireland at policy level.

7.19 Such a Directorate would have responsibility for setting out policies in details and for ensuring the operational impact through, eg. the Regional Health Authority and the new Education Authority. However, this Report recommends that for the initial strategic period the settings, stages and levels approach as outlined in Chapter 5 would be the firm basis for actions. This approach is outlined below.

RECOMMENDATION 1 - SETTINGS, STAGES AND LEVELS FOR ACTION

Settings for Action

Schools

- The Health Promoting Schools initiative has had some limited success in Northern Ireland, but needs to be properly resourced to have an impact. This is a vital area of work, given that early interventions in the school setting can be highly effective in enhancing protective factors and reducing risk factors for mental health.

Primary Care

- **Social prescribing** as a vehicle for offering patients in primary care alternative forms of support has been proven to be effective and should be encouraged.

- **Training for GPs** in mental health is required. Additionally, with the contracting system, GPs are particularly well placed to promote mental health.

Workplace

- The workplace is an important environment for the individual in life.

- Employers are under a general duty to take responsibility to ensure the health and safety of employees whilst at work. The law states that mental health should be viewed in the same light as physical health.

Further and Higher Education

- The Health Promoting University/College is an initiative which has been completed in England and elsewhere, and shown to be beneficial as promoting an organisation-wide culture based approach to the promotion of mental health. Its approach should be assessed for its usefulness in the Northern Ireland context.

Rural Areas

- As rural areas have been identified as particularly prone to risk factors such as isolation, problems related to the farming community and suicide, any suicide strategy needs to help raise awareness of the issues involved and help people in terms of where to get support.

Communities Including Marginalised Groups and Faith Communities

- Work needs to be carried out with a range of communities in Northern Ireland, with priority given to marginalized communities such as ethnic groups and also faith communities. Training in mental health issues would be beneficial for clergy for example.

Stages of Life

Children and Adolescents

7.20 There is evidence to show that enhancing protective factors and building resilience in children and adolescents helps reduce the likelihood of many mental health problems developing in later life.

7.21 Primary and secondary schools should implement appropriate programmes such as the RAP to enhance the mental health of the young.

7.22 We are including children and adolescents of all needs and abilities, and from a range of communities. Action in schools should also include action for those with special needs.

Older People

7.23 It is projected that by the middle of the 21st Century there will be in excess of 12 million older people in the UK. The quality of life of those with or without diagnosed mental health problems can be improved and can involve:

- reducing age discrimination;
- involving older people;
- early recognition or diagnosis of mental health problems to ensure patients receive prompt care; and
- meeting the needs of carers.

People in Receipt of Statutory Mental Health Services

7.24 Alternative, or adjunct treatments and forms of social support should be provided, at primary care level, such as social prescribing programmes. These can help reduce isolation, increase social inclusion and socialisation and maintain better mental health.

Levels of Action

Regional Level – Building Capacity

7.25 The effective delivery of mental health promotion in all sectors and settings in Northern Ireland will depend on building knowledge, expertise and capacity This should include (a) training, (b) information and guidance and (c) research.

7.26 **Training** - colleagues in many different sectors have the potential to promote mental health and will benefit from knowledge, training and support to promote psychological well-being and to identify early indications of difficulties. Training packages need to be designed to meet the different needs of different sectors and to recognise the specific context of promoting mental health in Northern Ireland. Training should be made available for a wide range of different sectors and professional groups eg:

- GPs;
- other primary care staff;
- teachers/university faculty staff;
- child care/early years workers;
- youth workers;
- priests, clergymen;
- community leaders;
- staff in a range of voluntary and community agencies;
- housing;
- occupational health and human resources;
- mental health services;
- mental health service users; and
- A&E staff.

7.27 **Guidance** – guidance and resources on implementing and evaluating mental health promotion should be made easily available and adapted, where necessary, for the Northern Ireland context. Examples of guidance from elsewhere in the UK include the English document "Making it Happen" (2001); and the wide range of resources produced as part of the Scottish Executive's National Programme for improving mental health and well-being (www.wellontheweb.net).

7.28 **Research** – the focus of the research should be on the promotion of positive mental health, rather than on mental illness. An integrated research policy should be established.

7.29 **Reducing discrimination and increasing awareness -** several actions within the existing regional strategy address these issues.

7.30 **Ensuring awareness** - of the relevant existing legislation such as the Disability Discrimination Act to tackle discrimination for example. Information should be sought on how many employers are aware that their duty of care relates to psychological well-being and reduction of stress in the workplace.

RECOMMENDATION 2 - IDENTIFICATION OF RESOURCES

7.31 A regional structure needs to be properly resourced in order to achieve its goals.

7.32 The resource allocation to create this structure should reflect the cost of mental ill health in Northern Ireland and should be in the region of £5-6 million over the initial 3 year period. With a commitment to sustainability for the future.

7.33 This figure has been calculated on a pro rata basis taking the Scottish model as an exemplar, but does not take into account the higher levels of deprivation and mental ill health in Northern Ireland than in the rest of the UK.

7.34 This initial seeding cost, allowing for the establishment of a Directorate would also facilitate over time additional funding streams to be made available from other sectors than the health budget, such as education and employment.

RECOMMENDATION 3 - SUICIDE PREVENTION

7.35 The Review considers suicide prevention to be an integral part of the broader scope of mental health promotion and has been included as Annex 2.

7.36 The Review, therefore, recommends that suicide prevention needs to be placed as a public health priority and a Regional Mental Health Promotion Directorate needs to ensure that a separate suicide prevention strategy is implemented as part of its overall responsibility .

7.37 A Taskforce was set up in the Autumn of 2005 to consider suicide. Since then, the document: “Protect Life - A Shared Vision”, the Northern Ireland Suicide Prevention Strategy 2006-2001 has been launched. The document recommends targeted action with specific at risk groups and in a range of settings.

7.38 It is recommended that such recommendations be ‘dovetailed’ with any mental health promotion strategies taken forward by the Mental Health Promotion Directorate.

Annex 1

MENTAL HEALTH PROMOTION

Committee Members List, Acknowledgements and Contributors

- Prof. Alan Ferguson (Convenor) - Chief Executive, NI Association for Mental Health
- Mr Eugene Caulfield - Administrator - Cavan/Monaghan Community Mental Health Services (retired)
- Ms Marie Crothers - Asst. Principal Social Worker/APM, Mental Health, Foyle HSST
- Mr Paul Fleming - Associate Dean, University of Ulster, Jordanstown
- Dr Liam Foy - General Practitioner, Quayside Medical Practice
- Dr Brian Gaffney - Chief Executive, Health Promotion Agency for NI
- Dr Yvonne Herbert - Clinical Psychologist, Belfast City Hospital
- Dr Oliver Hunter - General Practitioner
- Ms Judith Lee - Director of Education, NI Association for Mental Health
- Dr Graeme McDonald - Consultant Psychiatrist, Mater Hospital
- Mr Arthur McLean - Service User
- Ms Jean McMinn - Head of Counselling Service, QUB
- Mr Barry McGale - Suicide Prevention Co-Ordinator
- Ms Sheila Magee - Clinical Specialist (Physotherapy) - United Hospitals HSS Trust
- Mr Irwin Pryce - School Teacher
- Mr David Twyble - School Teacher (Retired)
- Rev Trevor Williams - Holy Trinity & St Silas (Joanmount) with Immanuel (Ardoyne)
- Mr Kieran Blaney - DHSSPS

The Review would also like to acknowledge its thanks for the contribution made to the work of the Committee by all those who contributed papers or who met with them personally. Particular thanks to Dr Lynne Friedli, Mental Health Promotion Specialist, Mr Gregor Henderson Director, National Programme for Improving Mental Health and Well-Being, Scottish Executive and Mrs Alison Deane, NIAMH.

The Review also acknowledge the contributions by way of papers/presentations made by the following:

"Theoretical Aspects of Mental Health Promotion" - Mr Paul Fleming & Ms Judith Lee

"Learning for Life & Work" - Mrs Helen Johnston, CCEA

"Some Thoughts on Prejudice, Stigma & Mental Health" - Rev Trevor Williams

"Post Traumatic Stress Disorder" presentation Mr Micky Duffy, Centre for Trauma & Transformation

"Some Thoughts on Mental Health Promotion in Primary Care" - Dr Liam Foy

"Issues Relating to the Structure of the Committee's Report" - Mr Eugene Caulfield

"Suicide Prevention & the Northern Ireland Mental Health Review, July 2004" - Mr Barry McGale

"Training in Mental Health Issues for Those Preparing for Ordination" - Rev Trevor Williams

"Mental Health Promotion for People with a Learning Disability" - Mr Maurice Devine, Nurse Consultant (Learning Disability) Down Lisburn Trust

"Interface Issues with other Working Groups" presentation - Ms Moira Davren, Child & Adolescent Expert Working Committee

"Mental Health Promotion Among Young People" - Mr Irwin Pryce, Mr David Twyble & Ms Jean McMinn

"Spirituality & Mental Health" - Rev Trevor Williams

"Promoting Mental Health: A Resource for Spiritual & Pastoral Care" (Church of England) - Presented by Rev Williams

"The Costs of Mental Illness" - Mr Michael Parsonage, Sainsbury Centre for Mental Health

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Annex 2

SUICIDE AND THE REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY (NI)

The World Health Organisation (2002) has reported that every year one million people across the world die by suicide. This equates to one suicide death every 40 seconds. They also advise that every year there are more people dying by suicide than by all the deaths due to the current conflicts across the globe.

This is equally true for Northern Ireland where the history of the conflict over some 30 years is well known. According to Fay et al (1997) found in the 25 years from 1969 to 1994, more people died here by suicide than as the result of the conflict. On average since 2000, deaths due to suicide have exceeded deaths on the road.

Suicidal behaviours place a heavy human and financial burden on society in Northern Ireland. Figures from DHSSPS (2002) indicate that there are on average 150 suicide deaths every year in NI, 80,000 working days are lost to illnesses related to attempted suicide; and that there are over 4,000 hospital admissions annually as the result of suicidal behaviour. The estimated annual cost to the economy of suicidal behaviour is £170m. Although suicide accounts for 1% of all deaths annually it equates to 7% of potential years of life lost, indeed the expected years of life lost to suicide is estimated to be 4,400.

Concerning the psychological and social impact on the family and society is estimated that up to 50 people are significantly affected by a suicide death, Bland (1994) cited by Campbell (1997), listed 28 different relationships to a person who died by suicide for those who came forward for help. If the figure of 50 is accurate, then each year in Northern Ireland 7,500 people are impacted as the result of suicide. Estimating the burden of suicide in terms of disability-adjusted life years (DALYs) in 1998 suicide was responsible for 1.8% of the total burden of diseases worldwide.

> *"This is equal to the burden due to wars and homicide, roughly twice the burden of diabetes, and equal to the burden of birth asphyxia and trauma"* (WHO, 2000).

Suicide Prevention Strategy

Reaction driven responses to suicide are costly in the short term, both financially and emotionally. A well planned, resourced and a co-ordinated strategy to suicide prevention would be cost effective in the longer term (Ramsey & Tanney 1996). Suicide is a multi-dimensional issue and the Australian Government highlight:

> *"The complexity of the interaction between risk factors, and the capacity for health care and social interaction to influence individuals choices, suggests that Government and society have a responsibility to act"* (Commonwealth of Australia 2000).

The moral obligation rests on the principle of beneficence (Kuitert 1995) and responses are required at the individual, community and Government levels.

Limitations of the Present 'Promoting Mental Health Strategy' Re. Suicide Prevention

It would appear that the Ministerial Group on Public Health did not take responsibility for the overall Strategy and Action Plan. As a result, a lack of strategic leadership, accountability and inter-departmental approach was evident.

The Implementation Group, whose task it was to report on progress, met infrequently and therefore, was unable to oversee and drive forward the actions. Furthermore, the financial resources and support were insufficient to deliver and ensure co-ordination on the actions.

Though the current Mental Health Promotion Strategy is to be welcomed, there is more involved in suicide prevention than mental health promotion. Mental health promotion plays a fundamental role in enabling the positive self-esteem of individuals. It also seeks to strengthen individual and community resilience. Suicide prevention initiatives build on these efforts by seeking to: raise awareness about suicide at the whole population level; seek to intervene with those at risk of suicide; follow up those who have attempted to end their lives and provide care and support for those bereaved by suicide.

The Benefits of a Regional Suicide Prevention Strategy

According to the US Government, a National Strategy for suicide prevention can:

- raise awareness and help make suicide prevention a national priority. This can help direct resources of all kinds to the issue;
- provide an opportunity to use partnerships and the energy of survivors to engage those who may not have considered suicide prevention within their purview. It supports collaboration across a broad spectrum of agencies, institutions, groups and community leaders as implementation partners;
- link information from many prevention programmes to avoid unintentional duplication and disseminate information about successful prevention interventions;
- direct attention to measures that benefit the whole population and, by that means, reduce the likelihood of suicide before vulnerable individuals reach the point of danger;
- bring together multiple disciplines and perspectives to create an integrated system of interventions across multiple levels such as the family, the individual, schools, the community and the healthcare system; and
- help develop in an equitable way and provide technical assistance with valuable types of expertise to strengthen community programme (US Department of Health and Human Services 2001).

An evidence-based strategy can maximise success when recommendations are implemented locally. Sound evaluation of community programmes, in turn, builds the evidence base.

The following goals outline the range of outcomes that would support the aim of a national strategy:

- Preventing premature death due to suicide across the life span.
- Reducing the incidence and prevalence of other suicidal behaviours.
- Reducing the morbidity associated with suicidal behaviours.
- Providing opportunities and settings to enhance resilience, resourcefulness, respect, and inter-connectedness for individuals, families and their communities (United Nations/WHO 1993).

An evidence base guiding strategic work on suicide prevention is essential.

> *"…there may be political and social imperatives to be seen to be doing something about suicidal behaviour…scientists need not necessarily be pessimistic about such programmes, even though they may not meet the rigorous criteria essential for scientific research"* (Goldney 2000).

The groundswell of opinion is that urgent action is required and international evidence exists to guide the way forward.

Recommendations

- A Regional Mental Health Promotion Directorate needs to ensure that suicide prevention is a regional priority and the proposed suicide prevention strategy is implemented.
- A broad coalition of suicide survivor representatives, suicide prevention activists, researchers and community representatives needs to be created for the development and implementation of the strategy.
- The strategy needs to address the issue from both a targeted approach ie. vulnerable groups and a population approach.
- Suicide prevention needs to be placed as a public health priority.
- The suicide prevention strategy needs to be developed with an identified action plan with target dates, responsibilities and be properly resourced.
- A system for collating data on self-harm in Northern Ireland should be established linking it to the European WHO Multi-Centre Study on Parasuicide.
- The recommendations within Safety First need to be co-ordinated and implemented on a regional basis.

- Closer co-operation between our colleagues, North, South, East and West, in keeping with Investing in Health recommendations, should be encouraged and supported.

- A postvention service needs to be made a priority. Co-ordination and enhancement of the care provided to those bereaved by suicide must begin immediately.

- A suicide prevention research centre must be supported and resourced where local and international evidence can be accessed.

- A major culture change is required in our society that encourages help-seeking as a sign of strength, not weakness.

- Community development is one of the foremost ways of advancing suicide prevention and should be promoted through capacity building.

- An intervention programme such as Applied Suicide Intervention Skills Training (ASIST) should be provided as standardised training for all those who work with vulnerable people.

- Training for those providing long term care to suicidal persons needs to be reviewed and developed.

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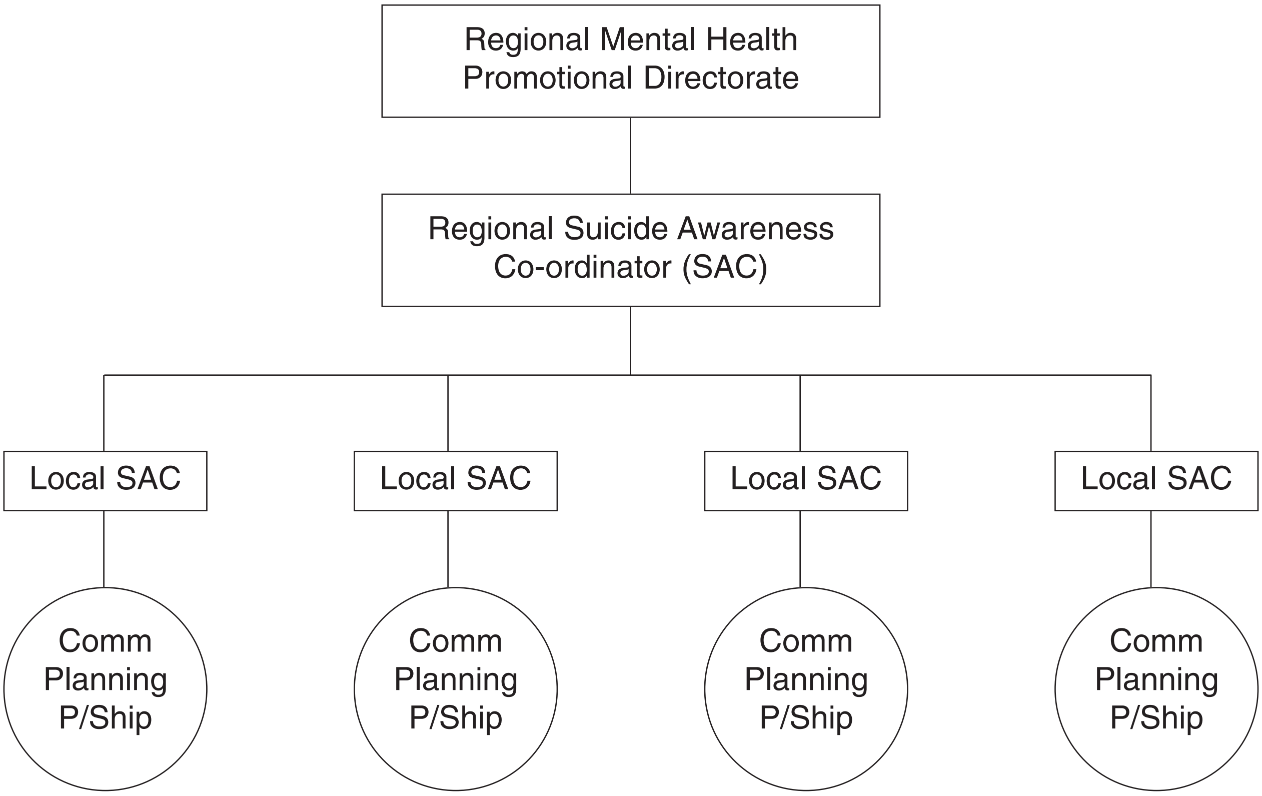
Proposed Implementation Framework



Annex 3

IDENTIFICATION OF NEED – SUMMARY OF KEY ISSUES

Promotion of Mental Health and Well-Being for All in the Population at Large

Key Issues to be Addressed

Home

- Factors which promote resilience in children under 5 help those children to do well despite adversity, therefore, early intervention is vital. Evidence shows, for example, that Promoting Parenting Skills Programmes improve the mental health of both parents and children. This is an area which should be further encouraged.

- Action 18 of the Strategy and Action Plan 03-08 relates to parenting skills and links with the ongoing work being undertaken to implement the teenage pregnancy and parenthood strategy and action plan.

- According to the Implementation Group’s (Strategy & Action Plan 08-08) Draft Annual Report, all HSS Boards are undertaking some action, for example the delivery of skills training to Surestart staff on building self esteem and handling child behaviour.

Schools

It is recognised that schools can have a vital role to play in protecting the health of young people. Interventions such as the Resourceful Adolescent Programme (RAP) in Australia and the Health Promoting Schools initiatives have been proven to be effective in promoting children’s mental health. Proper resources and cross-sectoral working are needed to implement a province-wide schools strategy. Whilst the current work being carried out in Northern Ireland on the Health Promoting School Initiative is valuable and points for the potential for the future, there are important issues which need to be addressed such as:

- **Funding** - a significant source of funding, long term needs to be identified and committed to such projects.

- **Cross-Sectoral Issues** - funding currently comes via the DHSSPS - with no involvement of the Department of Education. For an educational issue such as this, there needs to be a commitment by both the Department of Education and the DHSSPS for it to be successful.

- **Curricular Issues** - there should be a proper curricular approach, with the Health Promoting School Initiative dovetailing into other existing curricular programmes such as personal development.

- **Training** - teacher training needs to be reviewed, with teachers at the point of entry into teacher training, receiving proper training on mental health.

The Workplace

Employers have a duty under health and safety legislation to take measures to protect the health of their employees at work.

A negative working environment can lead to a range of problems such as: sickness absence labour turnover: bullying and harassment and ineffective working, what helps is to promote a healthy culture, with good quality of relationships, communication and support to staff.

- Policies should approach the topic in a comprehensive way, from recruitment and training, right through to actual support for vulnerable staff and guidance on handling issues such as staff sickness and absenteeism. Training for managers in implementing such a policy is recommended.

- All employers, as a minimum, should have in place a Mental Health in the Workplace Policy which seeks to address, even as a staged process over a period of time, issues relating to prevention of negative factors where possible, and support to those who may be in a stressful environment, or going through a difficult period.

Communities and Neighbourhoods

- Interventions designed to increase social inclusion such as social prescribing should be encouraged as part of community development.

- Actions in the Investing for Health 2002 need to be progressed and assessed.

- Research programmes addressing the needs of marginalized groups need to be resourced, with a view to mainstreaming.

- Training for relevant community and professional agencies on mental health awareness and ways to reduce stigma should be provided.

- The benefits of interventions such as arts on prescription for increasing social inclusion and strengthening communities should be explored especially in particularly disadvantaged areas.

- As the Communities That Care (CTC) Programme appears to have proved to have successful outcomes, not only in the USA, but elsewhere in Europe and the UK, this approach should be considered in Northern Ireland, especially with its particular needs and often fragmented social networks and lack of cohesion.

Further and Higher Education

- There are positive associations between education and both physical and mental health. Facilitating access to further and higher education opportunities for those who are psychologically vulnerable is an important issue in itself. In addition it is important for students, especially young adults, to feel supported in a pressured and transitional time in their lives.

- The Health Promoting University/College is an initiative which has been implemented in England. Its approach could be assessed for its usefulness in the Northern Ireland context.

Primary Care

Professionals

- **Training for GPs** – approximately 50% of GPs have no formal psychiatric training and few practice nurses have had such training (Croft 2000 in Foy 2004). As most GPs have opted to go into physical medicine, they may have very little experience of mental ill health. There is a need for better training for GPs.

- **Research** – increased research into the effectiveness of mental health promotion at primary care level is needed.

- **Resources, Targets and Priorities** – with the contracting system, there is the opportunity to target resources for mental health promotion. GPs are particularly well placed due to working within an overall health promotion setting, where potentially mental health promotion can be dovetailed with general health promotion initiatives.

- **Role of Voluntary Agencies** – there should be an increased use of services provided by voluntary agencies and increased direct liaison into primary care priorities.

Public

- **Support Available/Information Services** – primary care environments could be better used as an information resource, perhaps with access to a practice library with self-help literature.

- **Self-Help** – increased promotion of the ethos of empowerment for those who are vulnerable due to mental health problems would potentially speed recovery.

- **Users' Role in Promoting Mental Health at Primary Care Level** - there are opportunities for mental health service user groups in helping to improve mental health issues within primary care (Foy 2004).

Social Prescribing

- Social Prescribing including exercise, learning and arts of prescription, as an adjacent or alternative to medication have been proved to be effective elsewhere in the UK and internationally.

There is a need for this approach to be further employed in Northern Ireland.

Rural Areas

- As rural areas have been identified as being particularly prone to risk factors such as isolation and specific problems related to the farming community , and are particularly at risk of suicide, a province-wide strategy is required to help raise awareness of issues involved and to help people identify where to get support.
- Stigma has been identified as a major barrier in people seeking help – therefore, a strategy to address issues relating to stigma, especially young men in rural areas should be outlined.
- The actions relating to rural areas in the Strategy & Action Plan 03-08 need to be progressed.

Faith Communities

- An accepting and non judgmental attitude needs to be promoted – those in a caring role need not always "do" anything except listen and afford the individual dignity and respect.
- Training in mental health would be beneficial for those being ordained in all denominations.
- Information/workshops should be provided for those in the community who may benefit from pastoral care, and may not be affiliated to any particular faiths.
- The wider dissemination of the work of the Special Interest Group on spirituality within the Royal College of Psychiatrists may benefit practitioners not currently involved.

Prisons

- It is a major challenge to provide effective mental healthcare within a prison environment.

The Prevention of Mental Health Problems in Key At Risk Groups

Children and Adolescents

In terms of mental health promotion, early intervention and the development of emotional resilience have been identified as crucial in helping young people cope with pressures through adolescence into early adulthood.

- There is a range of potential interventions, school, home and community based which can be effective in this regard. Social skills training, eg. involving coaching and cognitive problem solving approaches is particularly effective with isolated children.

- The education and health sectors need to collaborate further on programmes with children and young people.

- Peer education and support can be a relatively cost effective approach, with considerable positive impact.

The Expert Working Committee on Child and Adolescent Mental Health will report in detail of issues relating to this target group in their report. Members of this Committee discussed with the Mental Health Promotion Expert Working Committee some of the main issues they seek to address in their report which include:

- child and adolescent mental health needs to be society's agenda – not just a healthcare issue solely;

- the education and health sectors need to work together;

- early attachment and infant mental health is important in later life;

- there should be quick and appropriate referral procedures in the event of first onset psychosis;

- there are significant gaps in child and adolescent services;

- "Looked After" children is an issue itself;

- access to support is important to young people – there is potential in peer education approaches;

- there is a regional strategy "Bright Future" but not enough emphasis on children;

- there needs to be a ministerial commitment to drive any such strategy forward; and

- other international and national models can be useful to draw upon, eg. New Zealand's Diversity Model and the Scottish "Pathway" approach.

People who are Deaf or Hard of Hearing

- One good practice example, from which Northern Ireland could learn, is that of the peer education process model adapted by the LINK Centre in Eastbourne.
- There is a need for research into this area in the UK generally and Northern Ireland in particular.
- Programmes to increase understanding and awareness of the issues relating to various types of deafness need to be implemented.

(Refer to A Strategic Framework for Adult Mental Health Services - June 2005 section of Services for Deaf People with Mental Health Problems.

People with a Learning Disability

The Learning Disability Expert Working Committee has reported in detail on these issues (Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland, September 2005).

Devine (2004) outlines 15 recommendations for actions.

These include:

- the need for mental health promotion for people who have a learning disability to be made more specific in mainstream strategies and policies;
- emphasis should be given within all relevant sectors to building positive mental health;
- a responsibility to enhance emotional well-being and build resilience should be a central component of any school curriculum; and
- there needs to be a recognition that people with a learning disability need to have improved opportunities for meaningful work/vocational opportunities.

Ethnic Minorities

- There is a need for greater public education and awareness about ethnic minorities in Northern Ireland.
- There is a need to further explore issues relating to the mental health of these groups.
- Research into identification of need would help to begin to address how to reduce barriers and increase social inclusion for the increasing number of ethnic groups in Northern Ireland.

Older People

- The prevalence of mental health disorders, such as depression, is relatively high in later life. Programmes such as pre-retirement, the provision of telephone support and prevention of suicide in later life should be implemented within the community.

- Community development programmes should be developed to enhance levels of social support for older people.

- Exercise on prescription through primary care should be encouraged.

People Affected by Unemployment

- Given Northern Ireland's higher levels of deprivation and unemployment, any regional strategy should directly address those issues with suggestions for strategic cross-sectoral action.

- It is essential for employers to have more education and awareness of mental health issues to ensure there is no discrimination against individuals seeking employment who have a background of mental illness.

- Any Northern Ireland strategy on prevention of suicide should include specific reference to dealing with unemployment (eg. it has been calculated that if there were full employment in the UK, the suicide rate would drop by 11%) (Lewis, Hawton and Jones 1997).

- Interventions with a strong focus on job search, self-efficacy, social and emotional coping skills and building social support should be encouraged.

People with a Physical Illness

Mental health and physical health are deeply interdependent. For the integration of mental health into general health care to be successful policy-makers and practitioners both need to be fully aware of the mind-body link. This is of particular importance at primary care level. Training is recommended for GPs and other professionals in mental health awareness.

For integration of mental health into general health care to be successful, policy-makers need to consider the following:

- general health staff must have the knowledge, skills and motivation to treat and manage people living with mental disorders;

- there needs to be sufficient numbers of staff with the knowledge and authority to prescribe psychotropic drugs at primary and secondary care levels;

- basic psychotropic drugs must be available at primary and secondary care levels;
- mental health specialists are required to provide support to monitor general healthcare personnel;
- effective referral links between primary, secondary and tertiary levels of care need to be in place;
- investment in primary and community care can deliver better outcomes both in primary and secondary care; and
- recording systems need to be set up to allow for continuous monitoring, evaluation and updating of integrated activities (WHO 2001 World Health Report).

People with Gender and Sexuality Issues

- The psychological and emotional distress of young gay men appears to be reasonably well documented. A gap in identified need seems to be that of young lesbian women's emotional and psychological needs.
- Given that questions over sexual identity can arise in adolescence and early 20' s, awareness amongst staff in school and further/higher education of these individuals' particular needs seems vital.
- Public education and awareness of gender issues to promote understanding and tolerance of them is required.
- Youthnet recommend as a result of their research that lesbian, gay and bisexual training, awareness training programs to all those involved in the development and implementation of services to gay people should be delivered.

People Traumatised by Sexual Abuse

- The importantce of sex education in schools needs to be highlighted.
- Sexual abuse should be talked about more openly, especially as many forms of abuse are linked to mental health problems.
- As sexual crimes are seriously under reported, training should be given to key relevant professionals in helping to identify hidden issues such as abuse and managing the disclosure of the same.

People Within the Criminal Justice System

It is recommended that it would be beneficial to take such action as:

- focusing on early interventions;
- research needs to be conducted into the mental health needs for women within the criminal justice system;
- encouraging the courts to use alternatives to custody for men with mental health problems who have committed minor offences;
- increase the number of court diversion schemes available across the country so that offenders who are acutely, ie. not at risk of suicide, can be given hospital places or the treatment they need;
- ensuring the Prison Service meets NHS Standards, policies and protocols, particularly regarding the use of medication, service user initiatives, training for doctors and healthcare staff; and
- continuing to explore in Northern Ireland the Restorative Justice Model which has also been proven to be effective as an alternative to long term imprisonment.

Improving the Quality of Life for People who have Experience in Mental Health Problems

The Key Issues to be Addressed

People with Enduring Mental Illness

The Strategic Framework for Adult Mental Health Services has recommended a Strategic Framework of Services in this area. However , in terms of mental health promotion, there is now a body of evidence to show that mental health promotion can contribute to the prevention of certain disorders, such as anxiety , depression and substance abuse. It can also contribute to the health improvement of people whether they are at risk of mental illness, as well as for those with mental health problems.

- An educational programme in Sweden improved the detection and management of depression. Evidence in England suggests that an educational package aimed at improving the interviewing skills of primary care physicians produced the same results.

It is suggested that this training could be applied here in a primary care setting, with all primary care professionals.

People with Eating Disorders

- Examples of good practice in terms of prevention indicate that the key issues to be addressed include: life skills training programmes and programmes which focus on improving self-image and reducing body dissatisfaction in young people.

- Given that early recognition means that treatment is most effective, in terms of mental health promotion, programmes should focus on early intervention.

People at Risk of Suicide

- Any new suicide strategy needs to be congizant of the UN/WHO guidelines and Safety First recommendations and needs to draw on good practice in the rest of the UK and the Republic of Ireland. It is imperative that in order for it to be implemented, it needs to be resourced with an identified action plan with target dates, identified responsibilities, etc.

- The Multi-Sectoral Task Force engaged with a wide number of individuals and organisations in drafting the document Protect Life - A Shared Vision 2006-2011.

- This document identified specific actions with a targeted approach eg. looking at the needs of those who self-harm; people with a mental illness; young males; marginalised and disadvantaged groups; and people who have been bereaved by suicide.

- Detailed recommendations on suicide prevention are presented in Annex 2.

People Emotionally and Physically Traumatised Due to the NI “Troubles”

- Over and above actual treatment, additional resources should be provided for day to day support and training of those who help people in the community affected by the conflict and to help enhance social capital.

- Consistent with WHO recommendations for post-conflict societies, preventive initiatives are required to reduce the onset of mental disorders such as anxiety, depression and PTSD focusing primarily on early interventions after trauma, rebuilding our community’s physical and mental health services and social infrastructures, mental health education and offering emotional, societal and economic support to victims (WHO 2004).

- The development and expansion of evidence based services, including CREST guidelines, to address psychological trauma and including adult survivors of childhood trauma should be taken forward as a priority.

People Involved in Substance Abuse

Both the Strategic Framework for Adult Mental Health Services and the Alcohol and Substance Report (December 2005) deal with the issues relating to people who have developed alcohol or drug problems:

- Availability of alcohol is a factor and, therefore, there may be political aspects to dealing with the problem away from excess drinking. Politicians should be lobbied in this regard.

- The Health Promotion Agency could have a significant role in developing a strategy province-wide to help promote healthier drinking, drawing on examples of good practice and research nationally and internationally.

Annex 4

WHO European Ministerial Conference on Mental Health

Facing the Challenges, Building Solutions

Helsinki, Finland, 12-15 January 2005

EUR/04/5047810/7
14 January 2005
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ORIGINAL: ENGLISH

Mental Health Action Plan for Europe

Facing the Challenges, Building Solutions

This Action Plan is endorsed in the Mental Health Declaration for Europe by ministers of health of the Member States in the WHO European Region. They support its implementation in accordance with each country's needs and resources.

The challenges over the next 5 to 10 years are to develop, implement and evaluate policies and legislation that will deliver mental health activities capable of improving the well-being of the whole population, preventing mental health problems and enhancing the inclusion and functioning of people experiencing mental health problems. The priorities for the next decade are to:

i. foster awareness of the importance of mental well-being;

ii. collectively tackle stigma, discrimination and inequality, and empower and support people with mental health problems and their families to be actively engaged in this process;

iii. design and implement comprehensive, integrated and efficient mental health systems that cover promotion, prevention, treatment and rehabilitation, care and recovery;

iv. address the need for a competent workforce, effective in all these areas;

v. recognize the experience and knowledge of service users and carers[1] as an important basis for planning and developing services.

This Action Plan proposes ways and means of developing, implementing and reinforcing comprehensive mental health policies in the countries of the WHO European Region, requiring action in the 12 areas as set out below. Countries will reflect these policies in their own mental health strategies and plans, to determine what will be delivered over the next 5 and 10 years.

1. Promote mental well-being for all

Challenge

Mental health and well-being are fundamental to quality of life, enabling people to experience life as meaningful and to be creative and active citizens. Mental health is an essential component of social cohesion, productivity and peace and stability in the living environment, contributing to social capital and economic development in societies. Public mental health and lifestyles conducive to mental well-being are crucial to achieving this aim. Mental health promotion increases the quality of life and mental well-being of the whole population, including people with mental health problems and their carers. The development and implementation of effective plans to promote mental health will enhance mental well-being for all.

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[1] The term "carer" is used here to describe a family member, friend or other informal care-giver.

Actions to consider

i. Develop comprehensive strategies for mental health promotion within the context of mental health, public health and other public policies that address the promotion of mental health across the lifespan.

ii. Adopt promotion of mental health as a long-term investment and develop education and information programmes with a long time frame.

iii. Develop and offer effective programmes for parenting support and education, starting during pregnancy.

iv. Develop and offer evidence-based programmes that foster skills, provide information and focus on resilience, emotional intelligence and psychosocial functioning in children and young people.

v. Improve access to healthy diets and physical activity for older people.

vi. Promote community-based multilevel interventions involving public awareness campaigns, primary care staff and community facilitators such as teachers, clergy and the media.

vii. Integrate mental health promotion components into existing generic health promotion and public health policies and programmes, such as those supported by WHO health promoting networks.

viii. Encourage the consumption of healthy products and reduce the intake of harmful products.

ix. Create healthy workplaces by introducing measures such as exercise, changes to work patterns, sensible hours and healthy management styles.

x. Offer effective mental health promotion activities to groups at risk such as people with enduring mental or physical health problems and carers.

xi. Identify clear mechanisms for empowering the population to take responsibility for health promotion and disease prevention targets, for example by heightening public awareness of the importance of life choices.

2. Demonstrate the centrality of mental health

Challenge

Mental health is central to building a healthy, inclusive and productive society. Sound and integrated public policies, such as those on labour, urban planning and socioeconomic issues, also have a positive impact on mental health and reduce the risk of mental health problems. The mental health implications of all public policy, and particularly its potential impact on groups at risk, therefore need to be considered. Mental health policy requires intersectoral linkages and should incorporate multisectoral and multi-disciplinary approaches.

Actions to consider

i. Make mental health an inseparable part of public health.

ii. Incorporate a mental health perspective and relevant actions into new and existing national policies and legislation.

iii. Include mental health in programmes dealing with occupational health and safety.

iv. Assess the potential impact of any new policy on the mental well-being of the population before its introduction and evaluate its results afterwards.

v. Give special consideration to the relative impact of policies on people already suffering from mental health problems and those at risk.

3. Tackle stigma and discrimination

Challenge

Mental health policy development and implementation must not be jeopardized by the widespread stigma attached to mental health problems that leads to discrimination. In many instances, people with mental health problems suffer from a lack of equal opportunities because of such discrimination. Human rights and respect for people with mental health problems must be protected. Empowerment is a crucial step towards meeting these objectives, as it enhances integration and social inclusion. The lack of empowerment of service users' and carers' organizations and poor advocacy hinder the design and implementation of policies and activities that are sensitive to their needs and wishes. The exclusion experienced by mental health service users, whether in asylums and institutions or in the community, needs to be tackled in a variety of ways.

Actions to consider

i. Instigate activities to counter stigma and discrimination, emphasizing the ubiquity of mental health problems, their general good prognosis and treatability, and the fact that they are rarely associated with violence.

ii. Introduce or scrutinize disability rights legislation to ensure that it covers mental health equally and equitably.

iii. Develop and implement national, sectoral and enterprise policies to eliminate stigma and discrimination in employment practices associated with mental health problems.

iv. Stimulate community involvement in local mental health programmes by supporting initiatives of nongovernmental organizations.

v. Develop a coherent programme of policy and legislation to address stigma and discrimination, incorporating international and regional human rights standards.

vi. Establish constructive dialogue with the media and systematically provide them with information.

vii. Set standards for representation of users and their carers on committees and groups responsible for planning, delivery, review and inspection of mental health activities.

viii. Stimulate the creation and development of local and national nongovernmental and service user-run organizations representing people with mental health problems, their carers and the communities they live in.

ix. Encourage the integration of children and young people with mental health problems and disabilities in the regular educational and vocational training system.

x. Establish vocational training for people suffering from mental health problems and support the adaptation of workplaces and working practices to their special needs, with the aim of securing their entry into competitive employment.

4. Promote activities sensitive to vulnerable life stages

Challenge

Infants, children and young people, and older people are particularly at risk from social, psychological, biological and environmental factors. Given their vulnerability and needs, young and older people should be a high priority for activities related to the promotion of mental health and the prevention and care of mental health problems. However, many countries have inadequate capacity in this area, and services and staff are often poorly prepared to deal with developmental and age-related problems. In particular, disorders in childhood can be important precursors of adult mental disorders. Supporting the mental health of children and adolescents should be seen as a strategic investment which creates many long-term benefits for individuals, societies and health systems.

Actions to consider

i. Ensure that policies on mental health include as priorities the mental health and wellbeing of children and adolescents and of older people.

ii. Incorporate the international rights of children and adolescents and of older people into mental health legislation.

iii. Involve young people and older people as much as possible in the decision-making process.

iv. Pay special attention to marginalized groups, including children and older people from migrant families.

v. Develop mental health services sensitive to the needs of young and older people, operated in close collaboration with families, schools, day-care centres, neighbours, extended families and friends.

vi. Promote the development of community centres for older people to increase social support and access to interventions.

vii. Ensure that age- and gender-sensitive mental health services are provided by both primary care and specialized health and social care services and operate as integrated networks.

viii. Restrict institutional approaches for the care of children and adolescents and older people that engender social exclusion and neglect.

ix. Improve the quality of dedicated mental health services by establishing or improving the capacity for specialized interventions and care in childhood and adolescence and old age, and by training and employing adequate numbers of specialists.

x. Improve coordination between organizations involved in alcohol and drugs programmes and children's and adolescents' health and mental health at national and international levels, as well as collaboration between their respective networks.

xi. Ensure parity of funding in relation to comparable health services.

5. Prevent mental health problems and suicide

Challenge

People in many countries are exposed to harmful stress-inducing societal changes that affect social cohesion, safety and employment and lead to an increase in anxiety and depression, alcohol and other substance use disorders, violence and suicidal behaviour. The social precipitants of mental health problems are manifold and can range from individual causes of distress to issues that affect a whole community or society. They can be induced or reinforced in many different settings, including the home, educational facilities, the workplace and institutions. Marginalized and vulnerable groups, such as refugees and migrant populations, the unemployed, people in or leaving prisons, people with different sexual orientations, people with physical and sensorial disabilities and people already experiencing mental health problems, can be particularly at risk.

Actions to consider

i. Increase awareness of the prevalence, symptoms and treatability of harmful stress, anxiety, depression and schizophrenia.

ii. Target groups at risk, offering prevention programmes for depression, anxiety, harmful stress, suicide and other risk areas, developed on the basis of their specific needs and sensitive to their background and culture.

iii. Establish self-help groups, telephone help-lines and websites to reduce suicide, particularly targeting high-risk groups.

iv. Establish policies that reduce the availability of the means to commit suicide.

v. Introduce routine assessment of the mental health of new mothers by obstetricians and health visitors and provide interventions where necessary.

vi. For families at risk, provide home-based educational interventions to help proactively to improve parenting skills, health behaviour and interaction between parents and children.

vii. Set up in partnership with other ministers evidence-based education programmes addressing suicide, depression, alcohol and other substance use disorders for young people at schools and universities and involve role models and young people in the making of campaigns.

viii. Support the implementation of community development programmes in high-risk areas and empower nongovernmental agencies, especially those representing marginalized groups.

ix. Ensure adequate professional support and services for people encountering major crises and violence, including war, natural disasters and terrorist attacks in order to prevent post-traumatic stress disorder.

x. Increase awareness among staff employed in health care and related sectors of their own attitudes and prejudices towards suicide and mental health problems.

xi. Monitor work-related mental health through the development of appropriate indicators and instruments.

xii. Develop the capacities for protection and promotion of mental health at work through risk assessment and management of stress and psychosocial factors, training of personnel, and awareness raising.

xiii. Involve mainstream agencies responsible for employment, housing and education in the development and delivery of prevention programmes.

6. Ensure access to good primary care for mental health problems

Challenge

For many countries in the European Region, general practitioners (GPs) and other primary care staff are the initial and main source of help for common mental health problems. However, mental health problems often remain undetected in people attending GPs or primary care services and treatment is not always adequate when they are identified. Many people with mental health problems, particularly those who are vulnerable or marginalized, experience difficulties in accessing and remaining in contact with services. GPs and primary care services need to develop capacity and competence to detect and treat people with mental health problems in the community supported as required as part of a network with specialist mental health services.

Actions to consider

i. Ensure that all people have good access to mental health services in primary health care settings.

ii. Develop primary care services with the capacity to detect and treat mental health problems, including depression, anxiety, stress-related disorders, substance misuse and psychotic disorders as appropriate by expanding the numbers and skills of primary care staff.

iii. Provide access to psychotropic medication and psychotherapeutic interventions in primary care settings for common as well as severe mental disorders, especially for individuals with long-term and stable mental disorders who are resident in the community.

iv. Encourage primary health care staff to take up mental health promotion and prevention activities, particularly targeting factors that determine or maintain illhealth.

v. Design and implement treatment and referral protocols in primary care, establishing good practice and clearly defining the respective responsibilities in networks of primary care and specialist mental health services.

vi. Create centres of competence and promote networks in each region which health professionals, service users, carers and the media can contact for advice.

vii. Provide and mainstream mental health care in other primary care services and in easily accessible settings such as community centres and general hospitals.

7. Offer effective care in community-based services for people with severe mental health problems

Challenge

Progress is being made across the Region in reforming mental health care. It is essential to acknowledge and support people's right to receive the most effective treatments and interventions while being exposed to the lowest possible risk, based on their individual wishes and needs and taking into account their culture, religion, gender and aspirations. Evidence and experience in many countries support the development of a network of community-based services including hospital beds. There is no place in the 21st Century for inhumane and degrading treatment and care in large institutions: an increasing number of countries have closed many of their asylums and are now implementing effective community-based services. Special consideration should be given to the emotional, economic and educational needs of families and friends, who are often responsible for intensive support and care and often require support themselves.

Actions to consider

i. Empower service users and carers to access mental health and mainstream services and to take responsibility for their care in partnership with providers.

ii. Plan and implement specialist community-based services, accessible 24 hours a day, seven days a week, with multidisciplinary staff, to care for people with severe problems such as schizophrenia, bipolar disorder, severe depression or dementia.

iii. Provide crisis care, offering services where people live and work, preventing deterioration or hospital admission whenever possible, and only admitting people with very severe needs or those who are a risk to themselves or others.

iv. Offer comprehensive and effective treatments, psychotherapies and medications with as few side effects as possible in community settings, particularly for young people experiencing a first episode of mental health problems.

v. Guarantee access to necessary medicines for people with mental health problems at a cost that the health care system and the individual can afford, in order to achieve appropriate prescription and use of these medicines.

vi. Develop rehabilitation services that aim to optimize people's inclusion in society, while being sensitive to the impact of disabilities related to mental health problems.

vii. Offer services for people with mental health needs who are in non-specialist settings such as general hospitals or prisons.

viii. Offer carers and families assessment of their emotional and economic needs, and involvement in care programmes.

ix. Design programmes to develop the caring and coping skills and competencies of families and carers.

x. Scrutinize whether benefit programmes take account of the economic cost of caring.

xi. Plan and fund model programmes that can be used for dissemination.

xii. Identify and support leaders respected by their peers to spearhead innovation.

xiii. Develop guidelines for good practice and monitor their implementation.

xiv. Introduce legal rights for people subject to involuntary care to choose their independent advocate.

xv. Introduce or reinforce legislation or regulations protecting the standards of care, including the discontinuation of inhuman and degrading care and interventions.

xvi. Establish inspection to reinforce good practice and to stop neglect and abuse in mental health care.

8. Establish partnerships across sectors

Challenge

Essential services which in the past were routinely provided in large institutions or were not considered as relevant to the lives of people with mental health problems are nowadays often fragmented across many agencies. Poor partnership and lack of coordination between services run or funded by different agencies lead to poor care, suffering and inefficiencies. The responsibilities of different bodies for such a wide range of services need coordination and leadership up to and including government level. Service users and their carers need support in accessing and receiving services for issues such as benefits, housing, meals, employment and treatment for physical conditions, including substance misuse.

Actions to consider

i. Organize comprehensive preventive and care services around the needs of and in close co-operation with users.

ii. Create collaborative networks across services that are essential to the quality of life of users and carers, such as social welfare, labour, education, justice, transport and health.

iii. Give staff in mental health services responsibility for identifying and providing support for needs in daily living activities, either by direct action or through co-ordination with other services.

iv. Educate staff in other related services about the specific needs and rights of people with mental health problems and those at risk of developing mental health problems.

v. Identify and adjust financial and bureaucratic disincentives that obstruct collaboration, including at government level.

9. Create a sufficient and competent workforce

Challenge

Mental health reform demands new staff roles and responsibilities, requiring changes in values and attitudes, knowledge and skills. The working practices of many mental health care workers and staff in other sectors such as teachers, benefit officers, the clergy and volunteers need to be modernized in order to offer effective and efficient care. New training opportunities must respond to the need for expertise in all roles and tasks to be undertaken.

Actions to consider

i. Recognize the need for new staff roles and responsibilities across the specialist and generic workforce employed in the health service and other relevant areas such as social welfare and education.

ii. Include experience in community settings and multidisciplinary teamwork in the training of all mental health staff.

iii. Develop training in the recognition, prevention and treatment of mental health problems for all staff working in primary care.

iv. Plan and fund, in partnership with educational institutions, programmes that address the education and training needs of both existing and newly recruited staff.
v. Encourage the recruitment of new mental health workers and enhance the retention of existing workers.

vi. Ensure an equitable distribution of mental health workers across the population, particularly among people at risk, by developing incentives.

vii. Address the issue of lack of expertise in new technologies of present trainers, and support the planning of “train the trainers” programmes.

viii. Educate and train mental health staff about the interface between promotion, prevention and treatment.

ix. Educate the workforce across the public sector to recognize the impact of their policies and actions on the mental health of the population.

x. Create an expert workforce by designing and implementing adequate specialist mental health training for all staff working in mental health care.

xi. Develop specialist training streams for areas requiring high levels of expertise such as the care and treatment of children, older people and people suffering from a combination of mental health problems and substance use disorder (comorbidity).

10. Establish good mental health information

Challenge

In order to develop good policy and practice in countries and across the Region, information has to be available about the current state of mental health and mental health activities. The impact of any implementation of new initiatives should be monitored. The mental health status and the help-seeking behaviour of populations, specific groups and individuals should be measured in a manner that allows comparison across the WHO European Region. Indicators should be standardized and comparable locally, nationally and internationally in order to assist in the effective planning, implementation, monitoring and evaluation of an evidence-based strategy and action plan for mental health.

Actions to consider

i. Develop or strengthen a national surveillance system based on internationally standardized, harmonized and comparable indicators and data collection systems, to monitor progress towards local, national and international objectives of improved mental health and well-being.

ii. Develop new indicators and data collection methods for information not yet available, including indicators of mental health promotion, prevention, treatment and recovery.

iii. Support the carrying out of periodic population-based mental health surveys, using agreed methodology across the WHO European Region.

iv. Measure base rates of incidence and prevalence of key conditions, including risk factors, in the population and groups at risk.

v. Monitor existing mental health programmes, services and systems.

vi. Support the development of an integrated system of databases across the WHO European Region to include information on the status of mental health policies, strategies, implementation and delivery of evidence-based promotion, prevention, treatment, care and recovery.

vii. Support the dissemination of information on the impact of good policy and practice nationally and internationally.

11. Provide fair and adequate funding

Challenge

Resources dedicated to mental health are often inadequate and inequitable compared to those available to other parts of the public sector, and this is reflected in poor access, neglect and discrimination. In some health care systems, insurance coverage of access and rights to treatment discriminate severely against mental health problems. Within the mental health budget, resource allocation should be equitable and proportionate, i.e. offering greatest relative share and benefits to those in greatest need.

Actions to consider

i. Assess whether the proportion of the health budget allocated to mental health fairly reflects the needs and priority status of the people with needs.

ii. Ensure that people with the most severe problems and the poorest in society receive the largest relative benefits.

iii. Assess whether funding is allocated efficiently, taking into account societal benefits, including those generated by promotion, prevention and care.

iv. Evaluate whether coverage is comprehensive and fair in social and private insurance based systems, on an equal level to that for other conditions, not excluding or discriminating against groups and particularly protecting the most vulnerable.

12. Evaluate effectiveness and generate new evidence

Challenge

Considerable progress is being made in research, but some strategies and interventions still lack the necessary evidence base, meaning that further investment is required. Furthermore, investment in dissemination is also required, since the existing evidence concerning effective new interventions and national and international examples of good practice are not known to many policy-makers, managers, practitioners and researchers. The European research community needs to collaborate to lay the foundations for evidence-based mental health activities. Major research priorities include mental health policy analyses, assessments of the impact of generic policies on mental health, evaluations of mental health promotion programmes, a stronger evidence base for prevention activities and new service models and mental health economics.

Actions to consider

i. Support national research strategies that identify, develop and implement best practice to address the needs of the population, including groups at risk.

ii. Evaluate the impact of mental health systems over time and apply experiences to the formulation of new priorities and the commissioning of the necessary research.

iii. Support research that facilitates the development of preventive programmes aimed at the whole population, including groups at risk. Research is needed on the implications of the interrelated nature of many mental, physical and social health problems for effective preventive programmes and policies.

iv. Promote research focused on estimating the health impacts of non-health sector policies, as there is a clear potential for positive mental health to be improved through such policies.

v. Bridge the knowledge gap between research and practice by facilitating collaboration and partnerships between researchers, policy-makers and practitioners in seminars and accessible publications.

vi. Ensure that research programmes include long-term evaluations of impact not only on mental health but also on physical health, as well as social and economic effects.

vii. Establish sustainable partnerships between practitioners and researchers for the implementation and evaluation of new or existing interventions.

viii. Invest in training in mental health research across academic disciplines, including anthropology, sociology , psychology , management studies and economics, and create incentives for long-term academic partnerships.

ix. Expand European collaboration in mental health research by enhancing networking between WHO's European collaborating centres and other centres with research activities in the field of prevention.

x. Invest in regional collaboration on information and dissemination in order to avoid the duplication of generally applicable research and ignorance of successful and relevant activities elsewhere.

Mental Health for Europe: Facing the Challenges

Milestones

Member States are committed, through the Mental Health Declaration for Europe and this Action Plan, to face the challenges by moving towards the following milestones. Between 2005 and 2010 they should:

1. prepare policies and implement activities to counter stigma and discrimination and promote mental well-being, including in healthy schools and workplaces;

2. scrutinize the mental health impact of public policy;

3. include the prevention of mental health problems and suicide in national policies;

4. develop specialist services capable of addressing the specific challenges of the young and older people, and gender-specific issues;

5. prioritize services that target the mental health problems of marginalized and vulnerable groups, including problems of comorbidity, i.e. where mental health problems occur jointly with other problems such as substance misuse or physical illness;

6. develop partnership for intersectoral working and address disincentives that hinder joint working;

7. introduce human resource strategies to build up a sufficient and competent mental health workforce;

8. define a set of indicators on the determinants and epidemiology of mental health and for the design and delivery of services in partnership with other Member States;

9. confirm health funding, regulation and legislation that is equitable and inclusive of mental health;

10. end inhumane and degrading treatment and care and enact human rights and mental health legislation to comply with the standards of United Nations conventions and international legislation;

11. increase the level of social inclusion of people with mental health problems;

12. ensure representation of users and carers on committees and groups responsible for the planning, delivery, review and inspection of mental health activities.

Annex 5

SCOTTISH NATIONAL PROGRAMME FOR IMPROVING MENTAL HEALTH & WELL-BEING

Work on Public Mental Health in Scotland is taken forward, facilitated and co-ordinated through the Executive's National Programme for Improving Mental Health and Well-Being.

This work forms part of the wider Scottish Executive agendas on Mental Health, Social Inclusion and Health Improvement/Public Health.

The National Programme is hosted within the Executive's Mental Health Division with national funding support from the Executive's Health Improvement Funds of £9m per annum.

Key Areas of the National Programme's Work

Raising Awareness and Promoting Mental Health and Well-Being

- Scotland's Mental Health First Aid (SMHFA) Course;
- by March 2008 over 300 SMHFA trainers will be trained delivering SMHFA courses to over 40,000 people;
- public information leaflets on mental health have been produced;
- mental Health Promotion national training programme to be rolled out across Scotland following launch in June 2005;
- preliminary work on public promotion of Positive Mental Health and Well-Being to start 05/06;
- making mental health and well-being a priority area for NHS Health Scotland over the next five years.

Eliminating Stigma and Discrimination

- continuing to fund 'See Me', Scotland's National Anti-Stigma campaign, approximately £700k per annum – 2005/2008.

Public Attitude Results 2004 compared with 2002

	% agreeing 2002	% agreeing 2004
I would keep a mental health problem a secret if I had one	50	45
People with mental health problems are difficult to talk to	20	15
Public should be better protected from people with mental health problems	35	24
People with mental health problems are often dangerous	32	15

- building on the success of the Dementia Awareness campaign and undertaking further campaigning activities;
- ensuring that work on inequalities and mental health is taken forward as part of general work on inequalities in health, and wider work on equality;
- Scotland has been asked by WHO Europe to help support and lead the co-ordination of work across Europe around the key theme of eliminating stigma and discrimination and promoting social inclusion.

Preventing Suicide

- ‘Choose Life’ is the Scottish Executive’ s National Strategy and Action Plan to prevent suicide in Scotland. £3m per annum (2003-2006) has been allocated across Local Authority areas in Scotland to develop local ‘Choose Life’ suicide prevention action plans in conjunction with Community Planning Partnerships.
- 32 local suicide prevention Action Plans now in place in each Local Authority areas, developed by local Community Planning Partnerships.
- Suicide ASIST Training – there are now 142 ASIST trainers in Scotland delivering the intensive, interactive workshop.
- Over 2500 participants have now completed the course.

This is part of a National Suicide Prevention Training Strategy.

Promoting and Supporting Recovery

Launch of Scottish Recovery Network (SRN) 16 December 2004.

- The first three in a series of SRN discussion papers have been published and include a review of important elements of recovery, a consideration of community involvement and issues on researching recovery.

- Stories will be gathered at events around Scotland and the outcomes used to influence SRN's future work.

- Development of training to promote and support recovery.

- SRN is currently engaging with up to 60 individuals to take part in an ambitious research project to gather personal testimonies of recovery from mental health problems.

- SRN is collaborating with the Royal College of Psychiatrists on a training day to be integrated into postgraduate education.

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THE BAMFORD REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY
(NORTHERN IRELAND)

A VISION OF A COMPREHENSIVE CHILD AND ADOLESCENT MENTAL HEALTH SERVICE

July 2006

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FOREWORD

This report from the Bamford Review of Mental Health and Learning Disability (Northern Ireland) is the latest to be endorsed by the Steering Committee and deals with child and adolescent mental health services.

As with the other Expert Working Committees in the Review, the Committee examining these services adopted an evidence-based approach, drawing upon existing relevant information and research, and, where necessary, commissioning research.

Its members consulted widely with stakeholders from both the statutory and voluntary sectors in the production of this report, learning from best practice initiatives across both sectors, here, nationally and internationally. Consultation meetings were held with children and young people themselves, giving them the opportunity to present their personal experiences of and views on the services designed for them. Their comments and contributions were enlightening and invaluable.

The report is, therefore, firmly grounded, and this adds weight to its findings and recommendations. These detail major deficits in child and adolescent mental health service provision in Northern Ireland. Many of the recommendations are aimed at correcting these shortfalls, in provision. While we recognise the resource implications of implementing these recommendations, we urge Government to begin this process as quickly as possible, so that children and young people can benefit from a range and level of mental health services, which will appropriately meet their needs.

I thank all those involved in the development of this report for their efforts and time over the last 2 years in developing this report and I commend it to you.

Roy McClelland (Professor)
Chairman
July 2006

INTRODUCTION

The Bamford Review of Mental Health and Learning Disability (NI) recognises that any review of Child and Adolescent Mental Health (CAMH) services must take a holistic view of the child. To this end a wide spectrum of views has been sought which we have represented in this report.

Mental health disorders in young people impact significantly on the lives of those affected, and on the quality of life of those around them. Wider society pays a high price for the failure to tackle these problems effectively. Collectively the cost is reflected in social disruption, poor educational attainment, physical and mental ill health, anti-social behaviour, and the financial cost related to each of these. Of specific significance in Northern Ireland (NI) has been the growing awareness of the impact of "Troubles related Trauma", the effects of sectarianism and the associated violence on children and young people.

The link between childhood disorders and the development of mental health problems in adulthood is now well established. Failure to address holistically children's mental health will condemn future generations to suffer from social exclusion with all its associated problems. In short, child and adolescent mental health is a public health issue and is everyone's business.

In NI, 27% of the total population are children, compared with 22% of the population in England. NI has a higher level of deprivation and has suffered from 30 years of civil conflict. Yet the staffing levels and resources allocated to CAMH services do not reflect this. At present the workforce profile of Child and Adolescent Mental Health services clearly shows them to be wholly inadequate. Despite many examples of good practice the overall quality, consistency and accessibility of services is so inadequate that urgent strategic action is needed to tackle these shortages.

This report addresses those groups with the most pressing needs and those which pose the most significant challenges to the delivery of services. It has not considered exhaustively the totality of mental health difficulties, or bio-psycho-social issues which may present to CAMH services. Nevertheless the vision outlined in Chapter 1, and many of the recommendations, will have significant read across to any child with a mental health difficulty which presents to CAMH services.

The report also recognises that children and young people have rights under the United Nations Convention on The Rights of the Child (UNCRC), to which the UK Government is a signatory. Any proposals for a comprehensive child and adolescent mental health service need to take account of all the rights contained in the UNCRC.

The structure of the report is as follows; Chapter 1 explains the principles that underpin the vision of a comprehensive CAMH service. In Chapter 2, demographic and epidemiological evidence are provided on the client base to which a CAMH service should be available. Chapter 3 provides an overview of the gaps in present services and the conditions in which CAMH services currently operate - a situation characterised by overwhelming need and chronic under-investment.

Chapters 4 to 7, address the specific developments urgently required to implement the vision for a reform and modernisation of CAMH services. Improvements to the organisational structure of CAMH services are considered in Chapter 4, particularly on the need for expansion of the conceptualisation of CAMH services from tradition 'mental health' workers, to the entire network of professionals and services surrounding and supporting the child.

Chapter 5 recommends services that should be developed to promote good mental health and prevent mental ill health amongst children. Chapter 6 details recommendations which will address the gaps in current services. Chapter 7 provides recommendations for enhancing the capacity of all CAMH services.

This report provides a new vision, a detailed roadmap for service development, and recommendations for the reform and modernisation of services for our children and young people. It presents key recommendations that are central to correcting the current shortfalls in provision. We urge Government to implement these recommendations, which are essential for a healthy future for the children, young people and the families of NI.

CHAPTER 1

A VISION OF A COMPREHENSIVE CHILD AND ADOLESCENT MENTAL HEALTH SERVICE

"I think CAMH services are good but sometimes they don' t give you what you're looking for ." - *Young person's comment,*

1.1 The vision contained within this report is of a comprehensive CAMH service. This involves an integrated array of statutory , voluntary and community services that have a shared goal of safeguarding the mental health of children in Northern Ireland (NI).

1.2 Child mental health has been defined in terms of:

- the ability to develop psychologically, emotionally, intellectually, and spiritually;
- the ability to initiate, develop and sustain mutually satisfying personal relationships;
- the ability to become aware of others and to empathise with them; and
- the ability to use psychological distress as a developmental process, so that it does not hinder or impair further development. [1]

1.3 The definition above describes mental health as both personal and social as well as providing the necessary foundation for both personal and social development. Recognition of the social aspects of mental health clearly delineates the need for 'systemic' and 'public health' approaches as well as individually-oriented therapeutic approaches to mental health provision.

1.4 It has been asserted that adopting a "dual continuum" conceptualisation supports a broad consideration of the needs of individuals experiencing mental ill-health. [2] Individuals may be understood at the same time to have some degree of *mental disorder* while also having personal resources, skills and attributes that indicate their level of*mental health*. This view promotes the need for equal consideration of the types of provision that aim to treat disorders and those that promote mental health.

1.5 The Review believes that the goals of a comprehensive CAMHS should embrace the promotion of mental health, the prevention of mental ill-health, and the provision of accessible and effective treatment services to those who have developed mental ill-health. Such goals require the integrated provision of services from a range of agencies including health and social services, education, youth justice, and the voluntary sector .

1.6 This vision of a comprehensive CAMH services is reflected in the recommendations of this report and is informed by the following principles which are shared by many service planners and providers and owe much to the joint work of *Stroul* and *Friedman* [3, 4.]

Comprehensive services. Children should have access to a comprehensive array of services that address the child's physical, emotional, social and educational needs in order to promote positive mental health.

Individualised services. Children who have mental health needs should receive individualised services. These services should take a holistic view of the child including family and community contexts. They should be developmentally appropriate and build on the strengths of the child, family and community in support of the child's mental health.

Minimum restriction. Children should receive services within the least restrictive, most normative environment that is clinically appropriate. Whenever possible, community resources such as social, religious and cultural organisations should be partnered with mental health and provider agencies to promote the child's healthy community participation.

Family-focus. The child's family or surrogate family should participate as a full partner in all stages of treatment planning and provision including implementation, monitoring and evaluation. The development of mental health policy at regional and local levels should include family representation.

Case management. Services to children with mental health needs should be organised by case management or similar mechanisms to ensure that the child can avail of multiple services in an effective, co-ordinated manner that can change in accordance with her or his changing needs.

Early intervention. CAMHS should incorporate systems and services to support the early identification and intervention for children with mental health needs to maximise the likelihood of positive outcomes.

Service transition. Young people with ongoing mental health needs should be guaranteed a smooth transition into the adult service system when they reach the age for adult services. This requires the provision of transition planning protocols to complement the case management process.

Cultural competence. CAMH services should be provided by individuals and teams with the skills to recognise and respect the values, beliefs, customs and language of Northern Ireland's increasingly culturally rich and diverse population.

Inclusivity. All children who require mental health services should be able to access those services regardless of physical, mental or developmental ability.

1.7 Mental health services for children in NI have received too little attention for too long and have suffered from a lack of coherent planning and investment. The recommendations in this report represent the minimum requirements for the realisation of the vision of a comprehensive CAMH service for NI.

CHAPTER 2

WHO NEEDS A CAMH SERVICE?

“I feel the service provided has been very useful, to my children and myself, discussing issues and learning little things about my children has helped me to cope with my child’s illness and also encourages my eldest son. Being a single parent I feel it is a support. ” - *Parent/carer’s comment*.

TERMINOLOGY

2.1 A CAMH service has responsibilities to children who experience, or are at risk of, experiencing mental ill-health. Different terminologies used across the medical, educational and social-care settings to describe the problems that children and adolescents develop may present some confusion. These reflect the varied training backgrounds of different professional groups and the differing emphases between disciplines in conceptualising issues of health and ill-health. Within specialist CAMHS, broadly speaking the bio-psycho-social model is influential. In health settings such as community paediatrics a more focussed medical model prevails. In order to better understand terms that may be used the following paragraphs will attempt to explain some of the differences.

2.2 Using the terminology of health professionals, mental ill-health is often thought of in terms of three categories: mental health problems, mental or psychiatric disorders and mental illness.

(1) Mental Health Problems may be reflected in difficulties and/or disabilities in the realm of personal relationships, psychological development, the capacity for play and learning, development of concepts of right and wrong, and in distress and maladaptive behaviour. They may arise from any number or combination of congenital, constitutional, environmental, family or illness factors. *Mental Health Problem* describes a very broad range of emotional or behavioural difficulties that may cause concern or distress. They are relatively common, may or may not be transient but encompass *mental disorders,* which are more severe and/or persistent.

(2) Mental or Psychiatric Disorders are terms used to describe problems that meet the requirements of ICD 10, [5] an internationally recognised classification system for disorder. The distinction between a *Problem* and a *Disorder* is not exact but turns on the severity, persistence, effects and combination of features found.

(3) *Mental Illness* is the description used for a small proportion of cases of mental disorder Usually, it is reserved for the most severe cases. For example, more severe cases of depression, psychosis and Anorexia Nervosa could be described in this way. [1]

2.3 In the Educational sector, educationalists may use the term *emotional and behavioural difficulties (EBD)* when the problems they encounter are severe, persistent and associated with other areas of difficulty. Another term in common use is *special educational need (SEN)* and this may apply to developmental/learning problems as well as to behavioural and mental health problems. EBD and SEN may overlap with each other and with mental health problems and mental disorders.

2.4 Within the social care sector there are a number of terms used to describe young people whose difficult behaviour is challenging to others and can cause distress. In the main these terms tend to describe behaviours that focus on those aspects perceived as negative. Behaviour difficulties in young people can be viewed as a common pathway by which a variety of underlying circumstances show up. Sometimes there is dissatisfaction with definitive medical diagnoses in that they can conflict with holistic models encompassing underlying social, emotional and psychological causes used in social care and educational approaches. Any focus on children's deficits must not ignore the environmental factors that contribute to behaviours and the fact that children will also have strengths or assets, which can be the basis for intervention. Supporting and encouraging the development of strengths, skills and assets rather than focussing largely on the eradication of "problems" is an important and increasingly recognized strategy in interventions and in building resilience to mental health difficulty. [6]

2.5 The advice contained in the Public Health Institute of Scotland Needs Assessment Report on CAMH [2] is worth repeating here. "No medical/psychiatric diagnosis should remove a child from the potential assistance available within the range of multidisciplinary children's services. In practice this will mean that practitioners both within teams and across each local area will need to engage in discussion about their diferences, with a view to developing shared accounts of the young person's needs and negotiation of the most appropriate paradigm for interventions."

Contextualising the development of Mental Health difficulties

2.6 Mental health outcomes are perhaps best understood as a function of the person, the environment and the interaction between the two. Risk factors are cumulative and have been identified as residing within the person (for example genetic vulnerabilities or psychological variables such as low self esteem) and within the wider systems with which the child interacts. These might include family variables such as marital discord, poor parenting or difficult relationships between family members. It may also include factors in the wider community such as inadequate networks of social support or the impacts of crime and poverty.

2.7 Bronfenbrenner [7] provided a model for understanding the impact of social systems on individuals. At the *micro-level* individuals are influenced by systems with which they have regular, direct contact such as family, school or home. At the *meso- and exo-levels* influence results from the links between micro-level systems such as home and school, or the family; and health service providers. The *macro-level* represents the manner in which prevailing ideology and social structure influence the individual's experience; for example, through the impact of gender roles and family structures or the impact of government policy.

2.8 Despite this established need to view the person in context, mental-health provision generally focuses its attention on assessing and addressing the feelings, thoughts and behaviours of individuals. Within CAMH services it is more likely that a family perspective will be included. A contextual approach, however, would suggest that CAMH services should have input to the range of systems, such as school and community that affect young people.

Demographics and Epidemiology

2.9 NI has a population of approximately 1.7 million cited in the Census 2001 of which:

- 451, 514 are less than 18 years (27%); and
- 398, 056 are less than 16 years (23%) (OFMDFM 2004).[8]

2.10 Very little epidemiological study of child mental health problems has been carried out in Northern Ireland and the rates of many problems and disorders have to be extrapolated from British and international studies. The influential study of 10,000 children aged 5-15 published by the Office of National Statistics (ONS) was only carried out in England, Wales and Scotland and did not extend to NI.[9]

2.11 In Great Britain (GB) it has been shown that 30 to 40% of young people may at some time experience a mental health 'problem'. Up to 20 % (depending on environment and circumstances) will have a diagnosable mental health disorder.[10]

2.12 However NI is distinguished by higher levels of socio economic deprivation, ongoing civil strife and higher prevalence of psychological morbidity in the adult population. It is likely therefore that the prevalence of mental health problems and disorders in children and young people will be greater in NI than in other parts of the United Kingdom (UK). The Chief Medical Officer's report *'Health of the public in Northern Ireland',* estimated that more than 20% of young people are suffering "significant mental health problems" by their 18th birthday.[11]

2.13 The prevalence of CAMH problems and disorders is clearly linked to deprivation. Vulnerable children include those exposed to a wide range of problems including social and educational disadvantage. Looked After Children (LAC), abused children, asylum seekers, refugees and homeless children may be particularly vulnerable and in need of protection and intervention.

2.14 Thus at the lowest estimated prevalence rate of 10% approximately 45,000 children and young people aged 5-15 will have a moderate to severe mental health disorder and require intervention from specialist CAMH Services in NI.[9] Lowest estimates suggest that 0.075% (340) will require inpatient services.[12]

2.15 The following are demographics/epidemiological factors that will inform and shape future development of services and practice.

Lifestyle

2.16 The health and wellbeing of young people was surveyed through the Young Persons Behaviour and Attitude Survey, 6,000 pupils aged 11-16 took part in the survey. The questions covered were smoking, alcohol, solvents, drugs and sexual experience. The proportion of pupils smoking, taking alcohol, misusing solvents or drugs and engaging in sexual activities increased with age. This survey indicates a need for health promotion.[13]

2.17 With reference to sexual orientation of young people in NI, 3 reports "Towards Better Sexual Health", "A Mighty Silence", and "SHOUT" identified the need for further developments to support young people with issues related to sexual orientation. [14 15 16]

Social Environment

2.18 There is considerable stratification of the population of NI. Many young people experience the benefits and opportunities that accompany affluence while many others live in poverty and deprivation in social circumstances that harbour personal dangers and discouragement. Social and environmental factors have been shown to have an effect on the wellbeing of young people and their families. In the prevalence study carried out by the ONS mental disorder was associated with factors such as gross weekly household income, number of children within the home, family type (e.g. lone vs. couple parenting) and educational qualifications of parent. [9]

2.19 Within NI 38% of all households presenting as homeless in 2001/2002 were families with children and young people. [17] Lone parent households reflect 22% of the 36% of households who have dependant children and young people. [8] 2,392 children and young people under the age of 16 were affected by divorce in 2001. [18]

2.20 Although NI is emerging from conflict, it is still a deeply divided society. Children and young people are inevitably affected and influenced by community tensions and can be directly caught up in violence. 1 in 6 of those who died in conflict were aged 19 or younger. Research continues to show the impact that the conflict has both on shaping the lives of children and young people and directly impacting on them as individuals. [19 20 21 22 23 24]

2.21 It is important to note that NI has a higher overall prevalence of mental illness of a magnitude estimated to be 25% higher than England.[25] This is an estimate of mental illness mainly in the adult population, however it can be assumed that rates in children may be similarly higher than in England.

Children with Complex Health Needs

2.22 Children with physical disability are at higher risk of developing mental health problems. [26] The rates of psychiatric disorder in 5-15 year old children with epilepsy were found in one study to be 37% compared to 11% in children with diabetes mellitus and 9 % in a control group. [27]

2.23 According to the 2001 Census of Population, 5.5% (24,966) of people aged under 18 reported having a limiting long term illness. This compares to 19.7% of the total population in NI. At November 2003, 13,102 people aged under 18 were claiming Disability Living Allowance. This equates to 2.9% of the population aged under 18 living in NI. A total of 552 children with visual or auditory impairments were in contact with health care in NI during 2002/2003. [8]

Children with a Learning Disability

2.24 "Children and adolescents with learning disabilities are children first, with health, developmental, social and family needs, within which their disabilities are only one set of contributory factors". [28] Children and adolescents with learning disability are proportionately more vulnerable to the full range of mental health disorders – typically about 40%. [29] Prevalence rates are 3-4 times higher in those with significant learning disability. [30]

Children with Autistic Spectrum Disorder (ASD)

2.25 Prevalence estimates for autism vary across studies. However according to recent reviews there is general agreement that ASD affects approximately 60 per 10,000 under 8 year olds of whom 10 – 30 per 10,000 have narrowly defined autism. [31] The need for a more integrated cohesive assessment and treatment service for this client group has been highlighted in a number of key reports including:

- Priorities for Action 2003/2004, [32]
- ASD: a guide to classroom practice [33]
- The Education of Children and Young People with ASD. [31]

Children at Risk of Suicide and Self Harm

2.26 Suicide and deliberate self harm are closely related phenomena although they differ in important ways. For example for some young people self harm is a coping strategy . The current UK National Inquiry into deliberate self harm (www.selfharmuk.org) which began in 2004 in the light of concern about increasing rates of self harm over the last decade reported that 1 in 10 teenagers deliberately self harm and more than 24,000 teenagers are admitted to hospital in the UK each year after deliberately self harming. These rates in the UK are the highest in Europe.

2.27 Suicide is a relatively rare event in childhood but increases in frequency in adolescence particularly among adolescent males reaching a peak in the early to mid twenties.Attempts at suicide are made by 2-4% of adolescents, rates being higher in those over 16 than those under 16. [34] The overall suicide rate in NI during the 3 year period from 1997 was 9.9 per 100,000 and those under 25 accounted for 21.5% of the total. Anecdotally media reports seem to suggest that suicide is on the increase amongst older adolescents and young adults in NI in recent years. The DHSSPS established a Suicide Prevention Taskforce to closely examine the issues involved which has reported back to Minister.

Children with Attention Deficit Hyperactivity Disorder (ADHD)

2.28 The estimated prevalence of this disorder is somewhere between 3 and 7% of school age (0-15) children. [35] It is reasonable to assume that the lower prevalence figure refers to the more severe cases necessitating referral to specialist services. On the basis of 2001 NI census figures of 476,906 children under the age of 18 this would approximate to 10,000 children. Currently only a small proportion of school age children with ADHD get referred to specialist CAMH services for assessment and treatment. A slightly larger percentage gets referred to Community Paediatric services. With increasing recognition of this condition in the community the numbers of referred children are likely to increase with significant resource implications for specialist CAMH and Community Paediatric services.

2.29 It is important to consider the significant criticism of the medical-diagnostic view that represents ADHD solely as a neuro-behavioural disorder and supports the widespread use of medication in the treatment of diagnosed children. A recent critique of the ADHD concept offered the following caution:

"*In our clinical experience, without exception, we are finding that the same conduct typically labelled ADHD is shown by children in the context of violence and abuse, impaired parental attachments and other experiences of emotional trauma*" [36]

Clearly there is a need to ensure that young people who present with such behavioural profiles receive the full range of appropriate assessments to identify the nature of their needs. Such provision should not be denied to any child or family on the basis that a young person's behaviour coincides with a diagnostic label. CAMH services should be resourced to provide such assessments, both relevant medical and non-medical.

Children with Feeding and Eating Disorders

2.30 The incidence of new cases of Anorexia Nervosa has increased to 11 per 100,000 per year, and bulimia to 18 per 100,000 per year. [37] Anorexia Nervosa is cited as the $^1/_3$ commonest chronic illness of adolescence [38] with over 50% of parents reporting one problem feeding behaviour, and over 20% report multiple problems, [39] in children aged between 9 months and 7 years old. Despite this, parents presenting at specialist services often describe difficulties in accessing treatment for their child, suggesting that at best care pathways are far from clear, and at worst that adequate services are not available to some patients.

Looked After Children (LAC)

2.31 It is by now well established that young people in care have markedly higher rates of mental health problems than the general population. [12] [40] Children looked after by Social Services in children's homes, foster homes and other residential placements often face complex and enduring interpersonal and mental health problems affecting every aspect of their lives and making it difficult for them to accept help and support and for staff and carers to maintain therapeutic relationships. The risk of breakdown of placements in foster care is anything between 40% and 60% and the risk of school expulsion and later social exclusion is extremely high. [41]

- There were 2,446 LAC in NI at 31st March 2003. Research conducted in Craigavon/Banbridge Trust indicated that up to 60% of young people in care within the Trust had diagnosable mental health disorders. [42] This is comparable to rates found in studies from other parts of the UK.

Demand on Social Services Departments

2.32 Demand on social services departments gives another measure of the scale of the challenge:

- In 2001/02 16,733 (approx 1 in every 27 children) children were referred to social services a total of 24,185 times.
- Of the children referred in 2001/02; 25% were under the age of 5, 33.3% were 5-11 years old, 30% were aged 12-15 years and 10% were aged 16 and over .
- There were a total of 15,167 episodes of involvement for children referred to social services in 2001/02, a slight increase (1.4%) from the previous year .
- 54.9% of these episodes of involvement were in relation to childcare issues, 25.5% were in relation to child protection issues, and 7.5% related to children with a disability. A further 5% to children whose well-being is likely to be prejudiced as a result of their behavioural, emotional, psychiatric or psychological disturbance and 3.0% were in relation to emotional, physical or developmental impairment as a result of family breakdown. Over the past 3 years there has been a decrease in the percentage of episodes of involvement for child protection while there has been a corresponding increase in those children involved with social services for childcare issues.

Children who have experienced Abuse

2.33 A significant proportion of children and young people in Northern Ireland has experienced or experience child abuse. On the 31st March 2002, there were 1,531 children and young people on the child protection register .[43] There were 2,270 child protection investigations in 2001/02 (50.3 per 10, 000 child, approx 1 in every 200 children), a figure that has been decreasing every year since 1998/99. [44] During 2003/04 the PSNI recorded a total of 5,335 offences (including assault, manslaughter, murder and cruelty) against children under 17.[45]

2.34 However it is important to note that many children who have experienced abuse do not tell of their experience at the time. The abuse may not come to light until much later in adulthood, if at all, and consequently , the number of children and young people impacted by abuse is much greater . [46] Many of these children are likely to have complex mental health needs.

2.35 Many children and young people at school in NI experience bullying as a serious problem. [47] In 2002, research reported by the Department of Education highlighted that 40% of primary school pupils had been bullied to some degree at school in the previous few months. [48] Research carried out on behalf of the Northern Ireland Commissioner for Children and Young People (NICCY) in 2005 identified bullying as a key priority for action.

Children who misuse Alcohol and Substances

2.36 As in the rest of the UK alcohol and substance misuse by children and adolescents in NI has increased. It has been shown that:

- 24% of young people who drank alcohol more than once a week had a mental disorder, three times the proportion among the group who had never drunk any alcohol;
- about one half of the 1 1 to 15 year olds who frequently used cannabis (more than once a week) had a mental disorder compared to those who use it less often or not at all; [94 9]
- the pattern of drug misuse and its impact is different in young people compared to adults - many adolescent drug misusers develop co-existing mental disorders but only a tiny number becomes dependent on the substance they use;
- the minimum cost of drug-related social problems is at least twice the Government's expenditure on law enforcement, supply reduction and prevention and treatment of substance use and misuse;
- substance misuse in NI has increased among 11-15 year olds throughout the 1990s. Population surveys addressing this age band show that 42% currently drink alcohol at least a few times each month. In addition 32% of boys who drink monthly report being drunk more than 10 times. Current drug use has increased from 5.6% in 1994 to 27.2% in 2003 in year 12 children;
- the risk factors for transition from use to misuse are known - poverty, inequality, social exclusion and homelessness contribute to serious drug problems; and
- the combination of alcohol misuse and smoking tobacco is a powerful gateway to illegal drug misuse.

2.37 Additional information of the specific alcohol and substance misuse issues amongst children and adolescents in NI is available in Chapter 8 of the report of the Alcohol and Substance Misuse Working Committee at www.rmhldni.gov.uk/

Children in conflict with the law (Youth Justice)

2.38 Criminal activity was surveyed in NI. [50] The results of the survey of young people (aged 14-18) show that young males are much more likely to experience adverse activity with the police than young females. The 1999 Juvenile prosecutions statistics show that 607 males aged 10-17 were proceeded against at the Magistrates' Courts compared to 69 females. 301 young people were admitted to custody. [51] The report "In our care" [52] makes important points about the relative lack of provision of mental health services to this group of children.

Children from Ethnic Minorities

2.39 NI is becoming an increasingly multicultural society and the needs of minority ethnic groups must be assessed and addressed. The needs of children of ethnic minority and migrant families have been unrecognised in NI and with the increase growth in numbers of migrant workers living in NI it is imperative to discover:

- can psychiatric disorders be recognised in these groups;
- do these children have specific symptoms and psychiatric disorders; and
- are psychiatric disorders more common in ethnic minority and migrant children.

2.40 The challenge for CAMH services is how to provide services to children and adolescents from ethnic minorities in an accessible and non discriminatory way . The response by the NI Council for Ethnic Minorities to the mental health review by O'Rawe on behalf of the Children's Law Centre 2002 is a helpful contribution.

CHAPTER 3

CURRENT CAMH SERVICES AND DEFICITS IN PROVISION

"I know my daughter more than you will ever know her…. I think my views are very relevant." - *Parental comment.*

In this chapter the current deficits in services to core client groups are explored more fully. A situation characterised by overwhelming need and chronic under-investment.

User and Carer views of current service provision.

3.1 The Review consulted widely with children and young people and their carers. In one particular consultation exercise, carried out early in the process, focus groups and a questionnaire study were used to explore service user and carer views and opinions about CAMH services. A more detailed account of this is described in Chapter 4 of this report and the full report is available at www.rmhldni.gov.uk It was suggested that there are fairly high levels of satisfaction with aspects of the service among people who are in ongoing contact with CAMHS. Significant areas of dissatisfaction, however, were also indicated.

3.2 Many users/carers spoke of their frustration with long waiting times and the limited availability of specialist services. There was concern about the lack of information available to the public about young people's mental health issues and the services available to young people and their families. While many users/carers described good relationships with CAMHS staff, many also described their disappointment with the outcomes of their contacts with CAMHS and some described how they felt CAMHS staff had not worked collaboratively with them and that they had not felt 'heard'.

3.3 The Review recognises the importance of working closely with users and carers to establish priorities for service design, delivery and evaluation

Age range for children's services

3.4 The upper age limits for access to services across and within health, education and social services can lead to difficulties accessing a comprehensive service across disciplines and can also lead to inequality of services. The situation is not entirely reconcilable as Education and Library Boards (ELBs) and social services departments are given differing age ranges of responsibility. Within the health personal social services (HPSS), there are certain disciplines and roles which have client age ranges built into them (e.g. school nurses, paediatric nurses) whereas the activities of other professions are more generic. The practice of specialist CAMH varies across the province in ways that are not dissimilar to services in other jurisdictions within the UK. In NI the upper age limit for acceptance into CAMH services varies from 14 to 16 to 18.

3.5 No CAMH services are adequately resourced at present to comprehensively address the needs of 16 and 17 year olds. Some flexibility is however essential. In some provider areas there has been flexibility with adult services taking responsibility for some or all 16 and 17 year olds but in other areas such flexibility has been lacking because of demands on adult services. In some provider areas CAMH services have continued to treat over 18 year olds.

Community Services

3.6 A detailed overview of the 4 Tier model is given in Chapter 4 of this report. The 4 Tier model has not been formally adopted in Northern Ireland regionally . However specialist professionals have tended to conceptualise current NI provision within this model.

3.7 NI CAMH services are delivered by a range of providers across the 4 HPSS Boards. The current services uphold the aspirations of the 4 tier approach[1]. However against a backdrop of resource constraint (workforce, financial, education, governance) progress in developing the 4 Tier model has been difficult and too many services, which are at present working with mental health issues in children and young people, are not conceptualized as part of CAMH services.

Community Services at Tier 1 and Tier 2

3.8 There has been limited development of Tier 1 services. Where developments have been made, for example in the Education and Voluntary Sectors, many of these services and projects do not yet conceptualise themselves as part of CAMH services. There is a need to ensure that those in contact with children have knowledge of children's mental health needs, and know how to refer to the appropriate specialist services. Collaboration between education, CAMH professionals, and colleagues in the non-statutory sector may aid the early identification of problems, however such collaboration is lacking.

3.9 Likewise developments in Tier 2 have been limited. Along with community paediatricians some areas have developed services for children with ADHD and ASD. For example some health visitors and clinical psychologists have developed services at Tier 2 using a behavioural and family counselling model addressing the developmental needs of young children up to final year in primary school. These developments are not NI wide. Other examples are as follows:

At Tier 1 and Tier 2

- Adolescent support services/projects are provided by a range of professionals and providers across the 4 current Boards. Links with specialist Tier 3 CAMH services are stronger in some providers than in others. Anecdotal evidence suggests that where links are stronger , projects can more successfully manage more complex problems without the need for full Tier 2/3 specialist team management of cases.

- Sure Start Early Intervention programmes continue to be established across the 4 Boards.

- Statutory and voluntary family centres contribute to Tier 1 and 2 services.

- A range of voluntary and community providers contribute to both Tier 1 and 2 services (i.e. befriending, advocacy services, educational input to schools)

- Education departments provide pastoral care and school based counselling services at Tier 1.

- Educational psychology, Educational welfare officer, emotional and behavioural support teams contribute Tier 1 and 2 services.

- Youth justice services are developing to support vulnerable young people with mental health needs.

Specialist Community Services Tier 2/3

3.10 Across NI there are specialist CAMH services in each of the Board areas. These are delivered by psychiatrists, clinical psychologists, specialist nurse therapists, and social work practitioners, and in some cases, family therapists and child psychotherapists. In reviewing the structure of these teams it became apparent that there are many differences in the operational and strategic policies, which define the roles of their services. Examples of these differences include:

- age limit for acceptance into services vary from 14 to 16 to 18;

- referral differences: although there are similarities in the core types of work that the teams tend to be involved in, there is a wide variation across teams in the type of cases with which they work. Special interests and specialist training acquired by staff and supported by their providers, have led to the development of services and innovative practice e.g. eating disorders, younger children team, Asperger's assessment clinics and social skills training in some teams;

- there is a wide variation in the length of waiting lists across NI ranging from 3 months to 'closed except for emergencies';

- teams are supported by other services within their own Board areas e.g., family centres, special social work projects for adolescents, clinical psychology and health visiting working at Tier 2 level and voluntary and community agencies, thereby facilitating specialist CAMH professionals to more effectively function as Tier 3 teams;

- a referral coordinator system operates in a number of providers. The link worker concept has also been developed in some providers. Only one service in NI has a dedicated full time manager;

- clinical networking with other services varies from provider to provider, and this impacts on the nature of the work in which the different specialist CAMH teams become involved;

- specialist CAMH services are under different directorates in different Boards e.g. children's services, mental health and disability, acute paediatric services;

- day hospital services are very limited; and

- specific Trauma services for children and adolescents exist in some areas.

Mental Health Inpatient and Secure Residential Care Units – Tier 4

3.11 Inpatient services and secure residential care services are delivered on a regional basis by separate providers.

- Child inpatient services under 14 years are delivered by Greenpark Health Care Trust on the Forster Green Site. 15 in-patient places but owing to operational difficulties only 10 can be used. 10 day patient places. The South Eastern Education & Library Board (SEELB) provides education through the Lindsay School.

- Adolescent services 14 years - 17 years delivered by South & East Belfast Trust currently on the Knockbracken site. 16 inpatient places are funded but owing to operational difficulties not all can be used. There is a day hospital service at College Gardens, Belfast.

- Muckamore Abbey Hospital is the site of a 15 place assessment and treatment inpatient provision for children with severe learning disabilities and challenging behaviour and delivered by North and West Belfast Trust. There are plans to relocate this service in the community.

- Secure residential provision for children and adolescents in the care system, many of whom have significant mental health needs, is delivered by the Ulster Community and Hospitals Trust in the Lakewood Unit.

3.12 However due to problems in recruiting staff neither of the first 2 units can admit to full capacity. A new build for adolescents (14- 17 years old) is planned for the Forster Green site, Belfast. This will provide 16 places and 2 intensive care places.

3.13 The NICAPS study of inpatient places in England and Wales showed that current provision of beds was not based on need. [53] The average was 3.4 beds per 100,000 under 18 population. Based on work by Kurtz et al [54] and NICAPS it is recognised that around 20 to 40 CAMHS beds are required per one million total population. [55] This includes places for younger children and for adolescents.

3.14 For NI, the above recommendations equate to between 32 to 64 places in total. The planned expansion of inpatient services on the Forster Green site would bring total inpatient places to 33 (18 for adolescents aged 14 – 17 and 15 for younger children aged under 14). Critically however, increasing the complement of inpatient places for adolescents will be dependent on the development and recruitment of an adequately trained workforce.

3.15 The “Secure Care Report” [56] made a number of recommendations in relation to the mental health needs of children and young people in secure accommodation including the development of protocols with CAMH services to inform the appropriate retention of children within secure accommodation or where necessary their transfer to inpatient adolescent facilities and the development of fast track procedures for assessment. Work is on this is ongoing.

Transition to Adult Mental Health services

3.16 The transfer of care between child and adolescent services and adult services usually occurs around the age of 18. Arrangements in NI at present could be considered informal and too dependent on local networks and professional relationships. Clearer guidelines and greater flexibility are required.

First Episode Psychosis

3.17 The incidence of psychosis begins to rise during the 15-18 year age range. There is some suggestion that the incidence in NI is higher than other parts of the UK but this needs further study. [57] Because of the differing age limits of services some are looked after by CAMH services and some by adult services with the result that in NI these young people get a very uneven quality of service. Early intervention services for psychosis have not yet been developed in NI.

Assertive Outreach

3.18 Assertive outreach provides frequent contact and co-ordinated intensive treatment with the young person and/or their carers by a multidisciplinary team. This is provided by a multidisciplinary team and can operate exclusively at outpatient level (outpatient assertive outreach model) or in conjunction with day patient and inpatient services.

3.19 In England and Wales some Tier 4 services have moved away from exclusive inpatient care and have developed models of assertive outreach and crisis intervention. This has provided much needed greater flexibility in meeting the needs of young people with complex mental health problems. It is recognised that improvement in provision for children and young people at specialist Tier 2/3 CAMHS will impact positively and decrease the number of those requiring Tier 4 service. However there is no capacity in existing CAMH teams in NI to provide such services.

Out of Hours and Emergency Provision

3.20 There are 3 main types of problems that commonly present as an emergency:

i) those with an identified serious mental health problem e.g. psychosis, depression, and rarely very serious eating disorder. There is often a need for immediate admission (within 24 hrs);

ii) young people presenting to a general hospital ward via Accident and Emergency (A&E) departments following an episode of or attempted self harm. The treatment needs are less clear in this group and in most cases admission to an acute paediatric or medical ward followed by next day assessment and follow up by Tier 2/3 CAMH services is appropriate; and

iii) children and adolescent with conduct disorders, out of control and challenging behaviour about which there is often inter-agency confusion and disagreement.

3.21 It would be expected that improved emergency provision in CAMH services would reduce Tier 4 demands.

3.22 No community CAMH service in NI can, within existing capacity , provide 24 hour cover to general hospital A&E departments. In some areas cover is provided by combinations of social services duty social workers for under 16s, and adult psychiatric services for over 16s in consultation with the limited numbers of CAMH consultant psychiatrists.

Paediatrics/Child Health

3.23 The NHS Health Advisory Service [1] and Audit Commission [58] reports on CAMH services estimated that 25% of the workload of community paediatricians is in the field of mental health. At this level many children with mental health problems and disorders (e.gADHD, ASD) are being seen in community child health settings. Apart from general practice this is the most common setting where children with mental health problems present.

3.24 Children with ADHD place considerable demands on both community paediatric and specialist CAMH services. Assessment involves consideration of whether there are alternative causes for restless inattentive and impulsive behaviour and whether comorbid conditions are present. Management involves liaising with schools and considerable time is taken up in coordination of services. Ongoing review of management programme and medication is required as the child gets older and transfer between community paediatric and specialist CAMH and adult mental health services can be difficult.

3.25 The extremely limited capacity of both community paediatric and specialist CAMHS in NI has mitigated against the development of joint clinics for assessment of ADHD and ASD locally although there are good examples of close collaboration for consultation and second opinions. Some community paediatric services have dedicated specialist nursing or psychology input to deliver psychological interventions in ADHD clinics.

Learning Disability Services

3.26 Current services are fragmented, differ in each provider and there are a variety of service models. There is a lack of clear referral pathways and processes. Intelligence Quotient (IQ) less than 70 is often seen as a cut off point between CAMH services and learning disability services in some Board areas and 55 or 65 in others. Lack of capacity in specialist CAMH service restricts the services that can be provided to moderate and mild learning disabled children and there is a significant shortfall of staff with the specific competencies to work with learning disabled children with mental health difficulties.

3.27 Children and young people with an IQ less than 50-55 generally come under the umbrella of services for severe learning disability. These teams may be part of a children's directorate or a general learning disability directorate and there is usually access to social services, community nursing learning disability services, allied health professionals, psychiatry of learning disability, psychology services and paediatric services.

3.28 Children and young people with a mild degree of learning disability, in health service terminology, receive a less structured service than those with severe learning disability and may be seen by CAMH services and other mental health services co-ordinated by the paediatrician and general practitioner. It is these children and young people who are likely to have difficulty accessing appropriate mental health services within either learning disability services or CAMH services due to the debates which occur regarding the cut off points by which services will accept referrals.

3.29 At Tier 4 children and young people with severe learning disabilities currently access inpatient facilities in a hospital for those with a learning disability.

Children with Autistic Spectrum Disorder (ASD)

3.30 Most of the difficulties have arisen due to inadequately resourced services for this client group. Higher functioning ASD is increasingly recognised. 75%, of the children who are now being diagnosed with ASD do not have a learning disability.[59] These children are therefore being referred to specialist CAMH and Community Paediatric services rather than learning disability services. This has led to an increase in the waiting times for specialist CAMH services and community paediatrics.

3.31 Children and adolescents referred to specialist CAMH services and community paediatrics in NI for assessment and treatment are in the main placed on routine waiting lists meaning that the families can wait for a considerable length of time. Such waiting times are unacceptable. There are often significant delays between diagnosis and the provision of support/treatment for children and families, causing further anxiety for the family.

3.32 Children with ASD have been described as 'perfect victims' when it comes to victimisation by their peers because of their profound lack of social skills[60] and long-term negative health outcomes for children in the general population have been attributed to peer victimisation with higher incidences recorded for depression, low self-esteem, anxiety, loneliness, and lower academic achievement.[61] [62] Interventions which focus on reducing isolation and integrating individuals into society are key to addressing the needs of these young people.[63] The need to promote social competence and integration for young people with ASD is not sufficiently addressed by current services in NI.

Looked After Children (LAC)

3.33 Children in substitute care are at increased risk of developing mental health problems. Risk factors for mental ill-health reside within the interacting domains of the child, the family and the environment, all of which are elevated for children who have entered care from homes that may be conflictual, seriously neglectful or abusive.

3.34 In most cases attachment experiences with carers may have been disturbed and self-esteem, interpersonal, emotional and intellectual skills inadequately developed. They may have difficulty making and sustaining friendships. They may be experiencing failure at school. Loss of significant relationships is almost always a significant issue and environmental contributors to emotional and psychological vulnerability – such as poverty, homelessness and discrimination are often present.

3.35 Coming into care can bring protective factors into the lives of young people who need this type of support - physical safety , better living conditions, fair and consistent rules to live by, understanding and acceptance from attentive carers and residential workers - all of which can support positive emotional and psychological development. Despite the best of intentions, however, the care system cannot emulate the constancy of family life and many young people in care have been so disturbed by their experiences that the activities and requirements of recovery can seem beyond their grasp.

3.36 These children have significant need for mental health supports in view of the levels of difficulty identified. [42] The delivery of services to this population is complex and can meet with impediments such as the impacts of high staff turnover rates in residential care [64] or multiple foster placements and unclear planning. [65] Traditional CAMH services have been limited in their ability to meet the needs of LAC, hampered by a number of factors including the unattractiveness of these traditional services due to stigma and a general lack of belief on behalf of the young people that services have any relevance to them. Within Great Britain (GB) the Quality Protects initiative has provided both impetus and resources for improved services to young people in care. [66] Within NI in recent years providers have begun to dedicate posts and, in some cases, teams to the provision of mental health services for young people in care. Developments are patchy , however , and there is a lack of regionally coherent planning and investment. Calls have been made for a specific mental health strategy for looked after children [67] which would assist the development of tailored, equitable services for this population.

Alcohol and Substance Misuse

3.37 The Alcohol and Substance Misuse Expert Working Committee of the Review have produced a report exploring in depth many of these issues. The report is available at www.rmhldni.gov.uk/ and specifically Chapter 8 deals with services to children and young people aged 17 and under.

3.38 In NI services are mostly delivered by voluntary and community sector but there is little multi-agency or partnership working between voluntary and community and statutory services at either Tier 2 or Tier 3.

3.39 The Health Advisory Service (HAS) report ‘The Substance of Young Needs’ [68] in arguing for the development of a 4 Tier approach to this problem, highlights a potentially crucial role played by CAMH services including:-

- arranging to add addiction skills to the assessment and treatment capabilities within CAMH Services;
- arranging to work more closely with drug and alcohol services;
- considering the feasibility of suitably trained staff being appointed to joint posts across a range of disciplines.

Children that are victims of Trauma

3.40 Recent research findings support observations gained through clinical practice that there are parts of NI severely affected by the legacy of the conflict. [69]

3.41 However it is important to remember that children suffer from the consequences of other traumatic experiences e.g. from experiencing road accidents, fires, assaults and other crimes. The Family Trauma Centre in Belfast and NOVA in SHSSB provide trauma services which include but extend beyond those who have experienced trauma from the conflict.

Feeding and Eating Disorders

3.42 At present, services for eating disordered children in NI are mainly provided by specialist community CAMH teams, using local paediatric wards or regional inpatient units when admission is necessary. Inpatient places in regional units have not always been sufficient to meet demand, resulting in considerable pressure on overstretched outpatient services in managing very ill young people in the community. Liaison with paediatric services is generally good. Adult mental health services generally assume responsibility for 18 years olds but some 16 and 17 year olds can be seen by adult disorder teams. Dietetics services provide services to some less severe eating disordered young people and support CAMH professionals in provision of both inpatient and outpatient services. 'On the ground' liaison between CAMH and dieticians is variable. Good initiatives with parent and carer support groups developed in association with regional units and local voluntary groups were noted.

3.43 The NICAPS study[53] found that, in addition to an eating disorders diagnosis and the burden of care on family members, factors that contributed to inpatient admission included ease of access to services, clinical experience of the referrer, the range of alternative to inpatient care, and the general backdrop of service organisation. The DHSSPS regional working group on eating disorders will develop service provision to this group of children and young people.

Services for Children and Adolescents with Challenging Behaviour

3.44 Children and young people who exhibit challenging behaviour and who also have complex needs present a major challenge for all the agencies involved. Agencies, both voluntary and statutory often struggle to find appropriate ways of meeting needs and enacting planned intervention. A lack of resources, long waiting times for Tier 2/3 CAMHS, and increased public expectation have led to many of these children and young people being managed within their own communities. This situation often leads to conflict in the management of the case with their carers and their community.

3.45 Community services often have to run with high levels of risk with little or no access to appropriate services, resources or consultation. Some children are managed in the community rather than residential care settings due to concerns that risks may multiply when they are placed in 'open care settings'. Community service capacity must be increased and services flexibly delivered to meet the needs of these young people.

3.46 The 'Children Matter' Review[70] reported a need for a small children's residential sector for those with emotional and psychological needs to support community and hospital services for adolescents. In other parts of the UK this is provided by the independent sector and such provision is almost nonexistent in NI.

Education

3.47 Schools in NI make a significant contribution to the positive promotion of mental health through enhancing self-esteem, encouraging sociability and promoting resilience in young people. More could be done through activities such as Circle Time, Circle of Friends, Nurture Groups, the teaching of emotional skills and also various Anti-Bullying programmes. Much of this work is pro-active and preventive and can act as a filter prior to the entry to Tier 1.

3.48 Schools however can also have negative effects on children's mental health. In NI pastoral care in some schools has not fully achieved its potential and when schools put too much emphasis on academic achievement, vulnerable children are often missed and may suffer as a result.

3.49 The work of specialist CAMH teams necessitates close liaison with teachers and educational psychologists and includes school observations and consultations. In NI there are different examples of joint practice in different areas of the province but all are limited by capacity issues. Joint working is known to require greater time investment. [71]

3.50 In addition to these areas of work, many schools in NI have dedicated counselling services available to vulnerable children and young people. These services are provided in a range of ways including individual counsellors employed by individual schools and services provided by independent providers. Evaluations of such services indicate they are highly valued by children and young people, parents and teachers, and that they benefit the mental health and wellbeing of children and young people who present with more serious problems. [72] [73] Many providers identified the need for close consultation and partnership work with local specialist CAMHS teams.

3.51 The development of Behaviour Management Teams and Autism Advisory Teams has also made an important contribution to supporting teachers which in turn has benefited young people's lives in many schools

3.52 It is recognised that non-attendance at school can be a pre cursor to other difficulties, many of which have mental health consequences and here the role of the education welfare services is evident. The development of Education other than at School (EOTAS) services has made a significant contribution to this issue and through networking; training and consultation, capacity to respond to mental health issues could be improved.

Forensic Services

3.53 There is no dedicated forensic CAMH service in existence in NI. Limited services are provided to individual young people by Tier 2/3 specialists on the basis of catchment area and by contracted psychology input to the secure residential facilities. Specialist Tier 2/3 CAMH professionals occasionally commit resources to advising the courts on matters relating to the welfare and needs of children when litigation or prosecution involves them. The volume of cases is such that contributions by mental health professionals are only possible in a minority of cases. In the future, there are likely to be more demands for mental health opinions. Most specialist services are not resourced or trained to respond.

3.54 A review of the mental health needs and services available to young people in regional care services and in the justice system has been jointly commissioned by DHSSPS and the Northern Ireland Office (NIO) and the report will read across to this Review .

3.55 The target group is those young people who present with severe disorders of conduct and emotion and neuro-psychological deficits or serious mental health problems who exhibit high risk behaviours and who have become (or are likely to become) involved in criminal proceedings through such behaviours as fire setting, physical and sexual assault. Those who raise most anxiety and sense of system powerlessness usually include:

- mentally disordered offenders (2 groups challenging behaviour and forensic);
- sex offenders and abusers;
- severely suicidal and self harming adolescents;
- very severely mentally ill adolescents;
- adolescents who need to begin psychiatric rehabilitation in secure circumstances; and
- brain injured adolescents and those with severe organic disorders.

3.56 Children and adolescents who fall into the client group appropriate to a forensic CAMH service are often highly mobile and frequently known to more than one agency Sometimes their moves between agencies and sectors of care are planned, but, all too often, referrals are made by the processes of exclusion, result from exhaustion of the capabilities of particular services, or are made in desperation as a last-ditch attempt to help. All too rarely does it seem that the care of individuals is subject to rigorously planned integrated care pathways.

Voluntary and community organisations and the statutory/non-statutory interface

3.57 In the course of the Review, note was taken of imaginative, successful and pioneering work in the broad CAMH field by voluntary organisations. Some examples of good practice are projects involving Belfast Central Mission, Barnardos, ContactYouth, New Life (Ardoyne) NI Association of Mental Health, NSPCC, Opportunity Youth, Extern (Turning Point), STEER, Threshold, and VOYPIC.

3.58 They are prominent in the direct provision of mental health services through helpline and other support services and through residential and day care provision. Their active role in the general promotion of good mental health among children and young people is self-evident. Much of their other work in the field is provided under the guise of generic children's services and therefore the full extent of their work is often hidden. There are a number of voluntary organisations working in partnership with CAMH services at all Tiers to support young people and their parents/carers. Voluntary groups can provide additional and innovative approaches to tackling mental health issues and promoting recovery after ill health. Church youth groups and organisations such as the YMCA also contribute at a community level to the promotion of good mental health in children and young people.

3.59 However, voluntary organisations are often prevented from long-term planning because of uncertainty about funding, thus services are often provided for a limited term and provision can be patchy, which leads to geographical inequity. The absence of a regional strategy for CAMH services has contributed to the situation where complementarity between statutory and non-statutory services is difficult to maximise. There can also be problems of communication such that statutory providers and service users are not always aware of services which are available through voluntary groups and partnerships, which could be mutually beneficial, do not exist.

Children with Sensory/Physical Disability and Enduring Physical Illnesses

3.60 Children who have physical disabilities and long-term health problems have higher rates of mental health problems.[27] Their parents may have higher than average rates of social welfare problems and relationship breakdown and their siblings higher than expected rates of mental disorder.

3.61 A small minority of children require care and treatment for their healthcare problems within the regional specialty centres. Examples are plastic surgery for children undergoing cleft lip corrections or for burns and neuropsychological treatments for head injured children or children with severe epilepsy. These may require specialist input from all sectors - education, social and psychiatric services.

Gaps and deficiencies in current CAMHS provision

3.62 As is demonstrated above, it is acknowledged that within NI there are limited services in a range of areas. Some services have been more developed in certain areas by professionals with a specialist interest e.g. eating disorders, autistic spectrum disorders and LAC. These services, where they exist, are limited and not equitably distributed across NI. Furthermore it is obvious that NI has a deficit in many areas when compared to other parts of the United Kingdom, Ireland and Europe.

3.63 It is revealing that the user and carer consultation summarised at the beginning of this section portrays dichotomised views which might be characteristic of NI CAMHS over the past 25 years. Positive experiences of CAMHS provision reflect the considered attention of committed staff as well as local-level innovation and good practice. The frustration expressed with regard to long waiting lists and the unavailability of specific services and information, on the other hand, reflects failure to develop services adequately due to a lack of regionally co-ordinated planning and investment.

3.64 O'Rawe[74] in her review of CAMHS in Northern Ireland carried out on behalf of the Children's Law Centre points out that the capacity of NI CAMHS to build on local examples of best practice is enfeebled by *"[t]he regional lack of priority and absence of accountability and co-ordination for NI CAMHS.."* She identifies an "..*ambivalence towards providing a comprehensive CAMHS..",* characterised by a regional lack of monitoring data and associated with the absence of regional strategic coherence and with "*profound and longstanding*" inadequacies in service provision on the ground.

3.65 Developments in the past 2 years have not significantly altered the situation noted by O'Rawe that, despite 25% of the NI population being younger than 18, expenditure on CAMHS represents less than 5% of the total NI mental health budget. Her assertion remains pertinent that failure to address the inequity of this situation will "… *potentially violate the [European Convention on Human Rights] and the statutory equality duty toward the most vulnerable mentally ill children and young people*".

3.66 In NI over the last 11 years, CAMH services have been developing from a very low baseline with a particular focus on the enhancement of Tier 3 community services and on an adolescent inpatient service. These developments have been hindered by the lack of a strategic or operational plan that lays out a phased and managed approach. The 1998 Policy Statement on Child and Adolescent Mental Health Services [75] addressed a number of key areas of policy and it is of concern that relatively little progress would seem to have been made since then, particularly in the areas of partnership and interagency/interservice cooperation and establishing user/carer involvement. This would seem to be related to difficulties in the Children's Service Planning (CSP) process. When implementing the existing and future strategies for the wider children services agenda, the development of a comprehensive CAMH service should be addressed across health, social services, education, and youth justice.

3.67 We contend that Child and Adolescent Mental Health is a public health issue, as evidenced by the demographic and epidemiological evidence in Chapter 2. A process for identifying public health needs of children with mental health problems should therefore be established to assist with the design and commissioning of statutory and non-statutory services.

3.68 One of the targets set in the CAMH policy statement was that a commissioning strategy for delivering services based on identified need, and meaningful and measurable objectives should be in place by 1 April 2000. While there has been some progress towards a commissioning strategy the issue of properly identifying need was never addressed. Any commissioning strategy without this will inevitably only be partially informed. A study of the mental health needs of children in Northern Ireland should be commissioned as soon as possible.

3.69 NI CAMHS remains a disaggregated service. O'Rawe noted the "fundamental need for a coherent, comprehensive regional CAMHS framework linked to an effective province-wide network of statutory and voluntary bodies promoting mental well-being in children and young people" (p. 13). The following chapter attempts to begin to address this primary deficit and addresses the observation made by O'Rawe that: " *NI CAMHS does not need a structural review – it needs a structure"*

RECOMMENDATIONS

1. The development of a comprehensive CAMH service should be facilitated by establishing a structured implementation process and, addressed across health, social services, education, and youth justice. It should include a process for identifying public health needs of children with mental health problems. *Para 3.66, 3.67, 4.66*

2. A study of the mental health needs of children in Northern Ireland, should be commissioned as soon as possible. *Para 3.68*

CHAPTER 4

THE FUTURE ORGANISATION OF CAMH SERVICES

"…maybe they need to say 'Right well maybe this isn't working, maybe we need to look at something else'. There seems to be a proliferation of ongoing treatment, just carrying on because we're there, something's better to be seen to be done than nothing, but there is no realisation, 'Hold on a wee minute, maybe we should look at some alternatives or maybe I'm not helping, we should change.'" - *Parental comment.*

This Chapter provides detailed proposals and recommendations for the re-organisation and expansion of the management and commissioning arrangements and relationships within child and adolescent mental health services. Together with chapters 5, 6 and 7 these recommendations, if implemented, would substantially reduce the gaps and deficits outlined in the previous chapter and deliver on the vision of a comprehensive CAMH service.

Developing an Integrated Children's Service System

4.1 In 'The optimal location for CAMHS – A response by Young Minds' [76] the following arguments were made for the organisation of CAMHS within children's health services:

i. there are significant differences between children's mental health services and adult mental health services particularly in relation to the developmental perspective integral to the former. Children's mental health services also have an important role to play in relation to prevention and early intervention issues and network with significantly different services to adult practitioners - notably education. Effective CAMHS planning needs to relate closely to the children's services planning process;

ii. there is a risk that adult services are always prioritised over children's services;

iii. both families and young people themselves are very concerned about the issue of stigmatisation and a link with adult mental health would compound this problem;

iv. the ethos of CAMHS is better understood by practitioners who work within children's health services than by adult psychiatrists;

v. medical referrals for mental health problems in children are as likely to go to paediatricians, especially those based in the community, as to child psychiatrists or clinical psychologists. School and pre-school children with behavioural problems are often seen by community child health services - where much Tier 1 and Tier 2 work takes place. Acute mental health problems frequently present to paediatric inpatient services. Structures which enhance close child health and CAMHS links are essential;

vi. community child health services, including health visitors and school nurses are actively involved in mental health promotion and preventative services; and

vii. professional contacts between psychiatrists will ensure that links with adult mental health are in any case maintained.

4.2 These points were considered when examining possible management and commissioning arrangements for a future comprehensive CAMH service. It was also noted that concerns had been expressed that the location of CAMHS within Children's Services Directorates, whilst promising considerable potential benefits in the provision of seamless care to children and their families, also carried with it a corresponding risk. That is, that within a management structure of such breadth the specific requirements and developments of CAMH services might be diluted by the requirements of the wider Children's Services agenda.

4.3 In consultation with colleagues in NI and the UK it was concluded that there was no weight of evidence which would suggest that this risk was greater within Children's Services Directorates than it was within existing relationships with adult mental health directorates. However to offset any risk of a dilution occurring it would be vital that the contribution of CAMH professionals is maximised within directorates. Existing models of good practice in this regard are available from Wales and the NHSSB.

4.4 It is recommended that, providers should develop Children's Services Directorates bringing together all aspects of children's services – Family and Child Care, Child Health, Disability and CAMHS – as a single system under common management. These HPSS services should then operate in partnership with children's services in other agencies – particularly education, youth justice, police and voluntary sectors – effectively as a single system.

4.5 It is vital however that any development is an evolutionary process which ensures that where existing management arrangements are working well service effectiveness is not compromised for the sake of an artificial deadline.

Education

4.6 There is a need to recognise the role of the education sector and its interface with children and young people. For this to be achieved, the place of schools within the service delivery framework must be specifically addressed rather than just added-on. The Department of Education and DHSSPS should set up an inter-departmental group to facilitate joined-up planning and commissioning of services in mental health and education and to develop the necessary collaboration in this field.

4.7 Schools have been found to be very effective settings for intervening in aggressive and acting out behaviours. [77] [78] This was recognised in the Audit Commission Misspent Youth report. [79] When interventions are delivered in schools it is vital to involve pupils in any initiatives to promote better behaviour. [80]

4.8 The crucial role and potential contribution of colleagues in the education sector (both through schools and youth services) must be recognised. Within this context the importance of school ethos and the characteristics of effective schools must be recognised. Any strategic development must enhance the capacity of such staff and ensure appropriate linkages to other parts of the CAMH service. Partnerships with other agencies will enhance the effectiveness of school based interventions and are to be encouraged in line with one of the key recommendations of this report. Practitioners in education need to have greater access to training in the necessary skills and knowledge to address children's and young people's mental health needs, including fostering positive mental health in the classroom, and referring to more specialised staff when appropriate.

Environment

4.9 CAMH services should be located in appropriate child friendly, non-stigmatising environments. Where possible they should be located on the same site as or as near as possible to other children's services as this facilitates networking and joint working.

Managed Networks

4.10 The concept of Managed Clinical Networks was first set out in the report of the Acute Services Review.[81] It was followed in February 1999 by Management Executive Letter (MEL),[82] which defined Managed Clinical Networks as: 'linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and Health Board boundaries, to ensure equitable provision of high quality clinically effective services….'[83]

4.11 The key ideas behind Managed Clinical Networks are as follows:

- emphasis on connection and partnership;
- distribution of resources rather than centralisation;
- maximising the benefits for all patients;
- erosion of barriers between secondary and primary care;
- emphasis on the term 'managed' in managed clinical network to underscore the importance of accountability and professional responsibility with a lead clinician having central importance; and
- networks are consistent with a renewed emphasis on the role of primary care in acute health care.

4.12 Managed Networks cross institutional and other organisational boundaries. Consequently they challenge existing planning and budgetary processes which are based around facilities or geographical areas. They rest on top of, or weave their way through static components of the overall service. They demand high levels of partnership between all those within the system as well as shared professional rotas and common clinical protocols. Clinical life needs to flow evenly across the network.[84]

4.13 In NI, fragmentation has resulted from services being delivered by multiple providers, some of whose focus has been acute health services. This has impacted upon the service delivery and efficiency of the specialist CAMH service. It is recommended that managed networks should be developed across all CAMH services in NI.

4.14 The evidence on managed networks suggests that when establishing networks, it is essential to get the balance right between formality and informality Network organisations should be dynamic and fluid operating through trust and strong relationships. Although networks need some hierarchy to operate effectively, too much bureaucracy will wipe out the benefits that a network organisation is designed to bring to the service. It is envisaged that networks would be both regional and local. The variety of health, social, educational, and voluntary sector inputs required in a CAMH service will necessitate local networks. When care requires strong links from general CAMH care to subspecialists then the region will be the only viable scale at which all elements of the service can be included, for example regional inpatient units.

4.15 Without good management and leadership in CAMHS, any refined systems will be useless. There is a need to strengthen the planning, commissioning and general management of CAMHS in NI. The roles and attributes of leaders and general managers, while overlapping, can be distinguished. CAMHS require management both at planning and service delivery levels. The skills required are not found solely in any one profession. Full time CAMHS managers should be recruited to cover populations of approximately 240 - 300,000.

4.16 A CAMHS Development Co-ordinator should be appointed by the new Strategic Health and Social Services Authority (SHSSA) to facilitate the development of management structures at both a local level and also of local and regional Managed Networks across NI. These developments would lead to a meaningful partnership between CAMH users, carers, commissioners, managers and providers in the identification of need, planning and evaluation of CAMH services for NI.

Models of Service Delivery

4.17 The Review undertook an extensive local consultation and a wide literature review , to identify the key components that any model of service delivery should have. It was agreed that any model must ensure prompt access into the system for young people and their families, as well as general practitioners, and other referrers. Any service model also needs to ensure that appropriate levels of care and effective transition arrangements for young people moving on to adult services are in place.

4.18 A number of different potential service delivery systems were examined. These are discussed in some depth in a paper available at www.rmhldni.gov.uk. It was clear that some of the organisational structures explored were unsuitable as models of service delivery, however cognisance was taken of the best practice ideas contained within each of them.

4.19 Of those systems and models examined, both within this report and by the Review in general, it was concluded that the 4 Tier model was the most effective at bringing together the diverse number of services from which children and young people might receive help, ranging from primary care, paediatrics, clinical psychology to specialist community services and highly specialist inpatient units. The model also has the flexibility to encompass services outside health and social services such as education, youth justice and the voluntary & community sector.

4.20 In addition, one of the recurring themes identified through-out the Review was that services and projects established by social services departments, youth services of the Education and Library Boards and by the voluntary sector are often doing preventative and interventive CAMH work. However they do not think of themselves as involved in the delivery of CAMH services. Such projects and services are integral to an effective service and there is a need for the development of relationships between them and specialist CAMH services. This would allow referrals to be directed most appropriately, and where needed, consultation by specialist CAMH services could be facilitated. It was concluded that the 4 Tier model would be most effective at cementing these relationships.

4.21 To ensure that all services are known to all agencies and to facilitate more effective collaboration and planning it is recommended that a CAMH service mapping exercise should be carried out across all sectors by an independent research institute, and repeated at regular intervals.

The 4 Tier Model

4.22 The Tiered framework has 3 main purposes, first and foremost it is intended to be a strategic and planning tool, secondly a communication tool. The third use is as a blueprint for how services are practically delivered on the ground. This framework allows for a more effective focus on the service functions required of a mature, effective and efficient CAMH service that spans the agencies involved and their working practices.

4.23 It is important to stress that whilst the 4 Tier framework is a useful conceptual tool, it should not be seen as something constraining or limiting to the development of CAMH services. The model is not meant to be hierarchical. Children and services do not fit neatly into Tiers and nor should they try to. There is a misconception that children and young people will move up through the Tiers as their condition is recognised as being more complex. In reality there will be some children and young people that may require services from a number or even all of the Tiers at the same time. The management of the networks across the Tiers will be crucial to maintaining flexibility. It is recommended that the 4 Tier model should be developed in NI, re-emphasising the flexibility of the model as it was originally conceived. When this vision is being implemented consideration should be given to which agency takes the lead responsibility for each Tier.

4.24 The model is divided into 4 Tiers of service with specific, but overlapping areas of responsibility. The diagram is an attempt to illustrate the functionality of the Tiers. These are described below:

Tier 1

4.25 Tier 1 offers interventions to children with mild to moderate mental health problems. Many of these are self limiting but may cause considerable distress in the child or family and disruption to the child’s learning. It is usually the first point of contact between a child and family with primary care, Education and/or voluntary and community agencies. Tier 1 staff includes GPs, other primary healthcarers, staff of child health services, school staff (teachers and counsellors), non-specialist children’s social workers and many non-statutory sector workers. This Tier should be accessible across NI. Only a very small proportion of children with these problems present to services and when they do present problems, they are frequently missed. The professionals will need generic training at this level. Services provided at this level will include:

- health promotion to prevent or interrupt the development of mental health problems;
- identification of mental health problems early in their development with early intervention;
- advice, and in some incidents treatment for less severe mental health problems (including emotional and behavioural problems);
- provision of support to enable families to function in a responsive manner to behavioural cues;
- enable families or carers to resolve parenting difficulties effectively;
- enable children to resolve their own emotional and or behavioural problems; and
- inclusion of children, young people and families as partners in the intervention process.

Tier 2

4.26 Tier 2 is the first line of specialist services. The staff include members of health-provided specialist CAMHS, community paediatricians, educational psychologists, specialist teachers, specialist children's social workers and some staff of voluntary organisations. They will need to have completed a dedicated training in the assessment and treatment of a range of mental health disorders. Tier 2 workers operate as individual practitioners, offering interventions for mental health problems and mental disorders. Not infrequently, staff will work as members of teams to which they may refer. Together, the functions delivered at Tier 2 are those required in each locality.

4.27 This Tier should be in a position to:-

- enable children and their families to function in a less distressed manner;
- promote services and activities to facilitate children to address and manage their mental health problems;
- assessment and intervention for children and their families with mental health problems;
- contribute to training, advice and consultation for people working at Tier 1 and 2
- assessment and appropriate referral to a range of other services; and
- inclusion of children, young people and families as partners in the intervention process.

Tier 3

4.28 Tier 3 services are more specialised. They are staffed by specialist CAMHS professionals from Tier 2 (para 4.26) who become Tier 3 workers when they function together as teams for particular children and families. Interventions are offered by professionals working in specialist multidisciplinary teams. They provide specialist services for more severe, complex and persistent mental disorders and illness. This group of professionals require specialist training opportunities. This service should be accessible across NI at a number of centralised sites. Tier 3 will provide:

- assessment and treatment of child and adolescent mental health disorders working with children and their families or carers;
- contribute to the training, advice and consultation to Tiers 1, 2 and 3;
- advice and education for families;
- feeding and Eating Disorder service;
- signposting to a range of other services;
- participation in research, development and audit projects;
- co-ordinating transition of children, adolescents and families to other Tiers; and
- inclusion of children, their families or carers and other agencies as partners in the process.

Tier 4

4.29 Tier 4 services deliver very specialised interventions and care for the most complex or uncommon disorders or illnesses. They include very specialised clinics that are only supportable on a regional or national basis, inpatient psychiatric services for children and adolescents, residential schools and very specialised residential social care. Partnership between education, youth justice, health and social services is essential at this level. This group of professionals require specialist training. These services will normally have the same profile of professionals as at Tier 3 and the range of services delivered may include:

- child & adolescent in-patient and day-patient services;
- secure and forensic services;
- feeding and eating disorder service;
- specialist team for neuro-psychiatric problems;
- specialist service for sensory impaired young people;
- specialist service for gender identity disorders;
- inclusion of children, their families or carers and other agencies as partners in the process; and
- contribute to training, advice and consultation to Tiers 1,2,3 and 4

Integrating Mental Health Promotion into Tiers

4.30 The key theme of this Review is the development of a holistic and integrated mental health service for children and young people that crosses organisational and institutional boundaries. Close partnerships and working relationships are vital to achieving this vision. Given that the Review has recommended the adoption of the 4 Tier model, it would be a missed opportunity not to examine the various planning and service commissioning models which exist in Social Services, Education and Youth Justice etc. Of particular note is the Hardiker model [85] of 4 levels of need, which is used extensively in Children's Services Planning (CSP). Given the similarity that exists between Hardiker and the 4Tier model, we believe that an opportunity exists for health and social services planners and commissioners to co-ordinate their services much more effectively. This would encourage the development of a common language across social care, education and mental health services and should be included in the remit of the interdepartmental working group recommended in para 4.6.

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Care Pathways

4.31 The notion of the care pathway is central to adopting the perspective of children, young people and their families, and in making patient-centred service improvements. The Scottish Executive's document 'The Mental Health of Children and Young People'[30] stated:

> *"A particularly important quality of functioning as an intelligent network is that participants envisage the care pathways which children and young people may need to take, and then act with their partners in the network to make that pathway – and inter-agency transitions in particular – as smooth as possible"*

4.32 Clear pathways of care both into and out of services should be developed. Models for improving the links between the 4 Tiers will necessitate the development of posts from the range of disciplines involved in CAMHS that can bridge both inpatient/residential and community services. These developments will help improve post discharge care and ongoing work in the community and will be a benefit accruing from a managed network.

4.33 As a priority the care pathway into Tier 4 services for children and adolescents with high risk, complex mental health needs must be defined. In most cases referral to CAMH Tier 2/3 services should provide the initial assessment and consultation with the child and family. In general, the Tier 2/3 service will remain involved with the young person in order to ensure continuity of care, maintain local community and family links and facilitate the resettlement of the child back into the community as they move from care in a Tier 4 service. Tier 4 services will need to work with the key agencies involved with children and young people to define the supported care pathways back into the local community .

Multi-disciplinary working

4.34 Multi-disciplinary teams can operate like small locally based networks, as ideally, they ensure that the appropriate professional provides intervention or that interdisciplinary support and advice are available. In practice, however, there is often a lack of clarity about a range of issues of importance to team function, such as the differing roles of core professionals. As well as having impacts on effectiveness, such issues can lead to tension within the multi-disciplinary team. One professional in a submission to the Review suggested:

> *The tensions involved in multi-disciplinary team working are extremely pertinent in terms of the direction and quality of the service delivered… (I)n terms of the stresses that can be generated, it is important that the tensions involved within such teams are recognised, acknowledged and addressed… A team...that does not address these issues is inherently flawed and will inevitably fracture. This may have devastating consequences for all concerned, but particularly for users.*

4.35 It has been suggested that the requirements for effective team-working include: clarity about rules, boundaries and expectations; autonomy; a high degree of participation; and supportive relationships.[86] With such clarity seemingly as elusive as the process involved in establishing it, it is not always easy to achieve 'supportive relationships'. The same issues arise in relation to multi-agency teams and the findings of the MATCH study[87] illustrate the nature of the difficulties. For example, the study demonstrated how team beliefs could impact on practice, and how such processes could marginalise some team members. The report offers practical strategies for good practice in multi-agency team-work at structural/organisational, ideological and procedural levels.

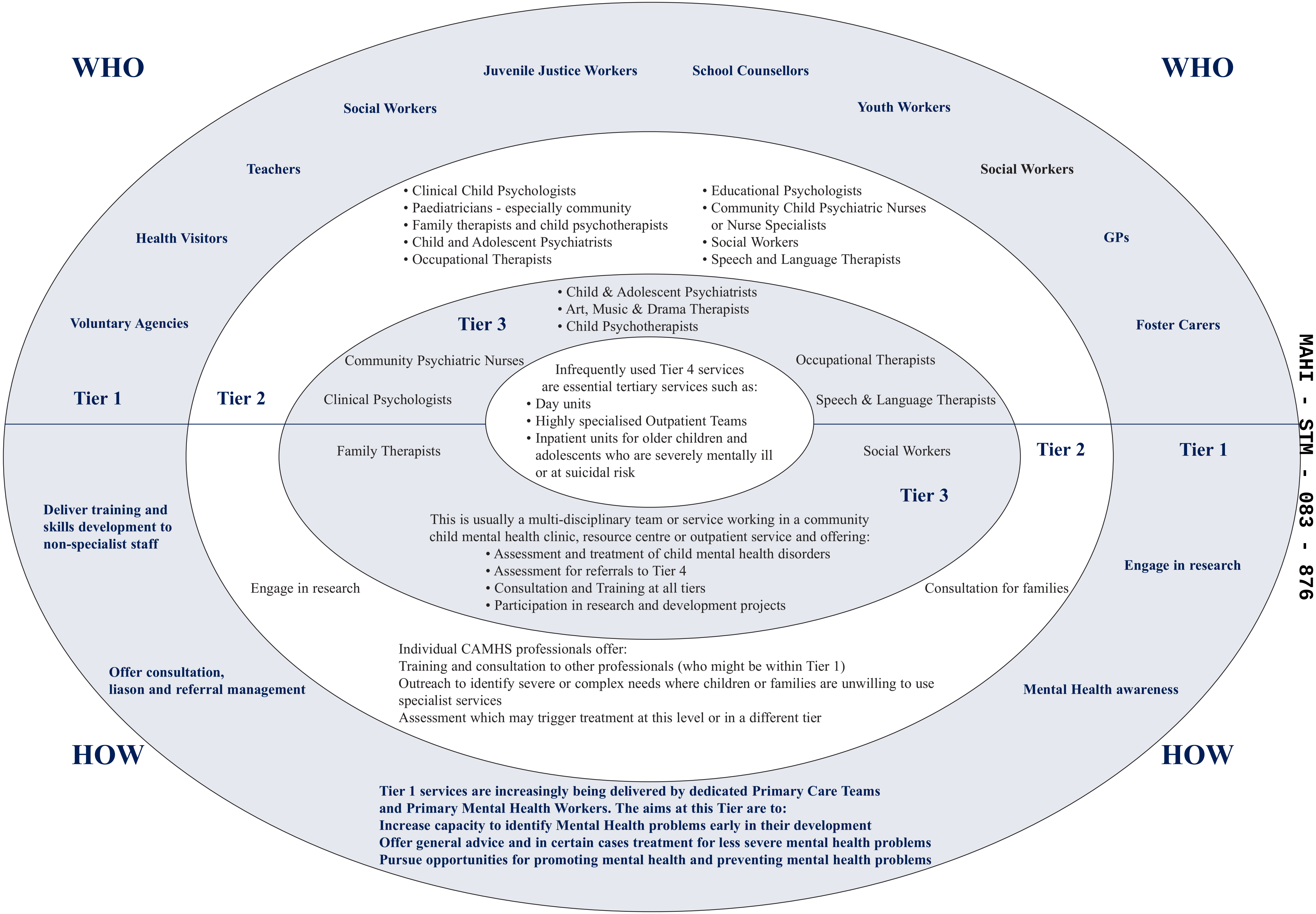
4.36 The professions currently represented in multidisciplinary CAMHS teams and how they relate to the aims of multidisciplinary assessment and treatment is subject to variation. A range of disciplines may be involved in gathering information relating to the bio-psycho-social perspectives of a comprehensive assessment. Systemic, narrative or psychodynamic perspectives might be added to enhance the assessment's holistic value. There is, however no widely agreed set of components to such an assessment, and therefore no clear consensus on the competency requirements within a team to achieve it. Also the hierarchical organisation of teams is not explicitly related to their function. Within NI, for example, a majority of teams appear to be 'psychiatry-led'. Examples exist in Great Britain and elsewhere of teams where professional inputs are specified but the lead can be provided by any of the professions involved.

4.37 In view of these issues we consider that a review of multi-disciplinary and multi-agency CAMHS working is required to inform the future planning and commissioning of services at Tiers 3 and 4. Clarity is required with regard to purposes, methods of functioning, and required competencies for specialist mental-health teams. This should include a review of which are the 'core' disciplines and competencies required in specialist teams and the implications in terms of representation of professional groups. Such a review - which would be consistent with the current Knowledge and Skills Framework agenda - should also address the stresses involved in multidisciplinary working, and should form an aspect of the early working brief of the CAMHS Development Co-ordinator.

Paediatrics/Child Health

4.38 Paediatricians and staff of most other disciplines who work in child health services have a vital role to play in developing mental healthcare. They have an influential place inside of a web of professional relationships involving education, social services departments and primary healthcare as well as voluntary and community agencies. They are best thought of as a part of Tier 2 services.

4.39 Child health services should be seen by all concerned as an essential part of a system of integrated CAMH service. Conversely specialist Tier 3 CAMH services should be viewed as making a key contribution to children's health and to paediatric care. This is a two way process and specialist CAMH services should aim to develop closer links with paediatricians. For many Tier 2 staff this can be provided by offering access to Specialist CAMH colleagues for consultation and support.



WHO

WHO

Tier 1

Juvenile Justice Workers

School Counsellors

Social Workers

Youth Workers

Teachers

Social Workers

Health Visitors

GPs

Voluntary Agencies

Foster Carers

Tier 2

- Clinical Child Psychologists
- Paediatricians - especially community
- Family therapists and child psychotherapists
- Child and Adolescent Psychiatrists
- Occupational Therapists

- Educational Psychologists
- Community Child Psychiatric Nurses or Nurse Specialists
- Social Workers
- Speech and Language Therapists

Tier 3

- Child & Adolescent Psychiatrists
- Art, Music & Drama Therapists
- Child Psychotherapists

Community Psychiatric Nurses

Occupational Therapists

Clinical Psychologists

Speech & Language Therapists

Family Therapists

Social Workers

Infrequently used Tier 4 services are essential tertiary services such as:
- Day units
- Highly specialised Outpatient Teams
- Inpatient units for older children and adolescents who are severely mentally ill or at suicidal risk

Tier 3

This is usually a multi-disciplinary team or service working in a community child mental health clinic, resource centre or outpatient service and offering:
- Assessment and treatment of child mental health disorders
- Assessment for referrals to Tier 4
- Consultation and Training at all tiers
- Participation in research and development projects

Tier 2

Engage in research

Consultation for families

Individual CAMHS professionals offer:
Training and consultation to other professionals (who might be within Tier 1)
Outreach to identify severe or complex needs where children or families are unwilling to use specialist services
Assessment which may trigger treatment at this level or in a different tier

Tier 1

Deliver training and skills development to non-specialist staff

Engage in research

Offer consultation, liason and referral management

Mental Health awareness

HOW

HOW

Tier 1 services are increasingly being delivered by dedicated Primary Care Teams and Primary Mental Health Workers. The aims at this Tier are to:
Increase capacity to identify Mental Health problems early in their development
Offer general advice and in certain cases treatment for less severe mental health problems
Pursue opportunities for promoting mental health and preventing mental health problems

4.40 Specialist CAMH services should continue to develop their services for ADHD and ASD in conjunction with Community Paediatric services. These services should agree and develop clear referral pathways and guidelines for the assessment and treatment of ADHD and ASD. Within a number of Trusts in NI, specialist CAMH posts have been established at Tier 2 to work with paediatricians to provide assessment and psychosocial intervention alongside or in place of medical care. Such service models support quality provision. When resources permit, joint clinics should be developed for assessment and management of the more complex cases.

Age Range of Services

4.41 The provisions of the key legislation that underpins child care, the Children (Northern Ireland) Order 1995, should guide the policy decision on the appropriate age range of services for CAMH services.

4.42 It is recognised however that this policy is not applied or applicable in the HPSS in all areas currently and that extending the age range for CAMH services at local level will need to take account of the resources required to meet the increasing incidence of mental illness in later adolescence.[88] It is estimated that because 16 and 17 year olds are particularly likely to have expensive to treat mental health problems the cost of a comprehensive CAMH service that includes 16 and 17 year olds may be twice as much as a service for 0 -16 years olds.

4.43 Adult mental health services need to be able to allow young people with mental illnesses, who are developmentally mature, early access to adult facilities. This is particularly important in the matter of early intervention services for psychosis. Generally however CAMH services should ordinarily cover children and young people up to their 18th birthday.

4.44 With regard to inpatient services the committee share the widespread concern about adolescents being admitted to adult psychiatric wards and note the view that such admissions are “unacceptable.” The Royal College of Psychiatrists[89] has already recommended that young people under 16 should not be admitted to adult wards, and those aged 16 and 17 should be admitted only under special circumstances. We support this view and recommend that young people requiring inpatient treatment should be treated in developmentally appropriate settings.

4.45 At times, children and young people with psychiatric disorders will be admitted to general paediatric or adult wards, or to adult psychiatric wards, in a crisis situation and because it is not feasible to transfer the patient to a psychiatric inpatient facility for children or young people. This may be because such facilities are remote, or because they are unable to offer a place. Admission to general wards or to adult psychiatric wards can provide a temporary place of safety and care, but must only be a short-term arrangement.

4.46 Psychiatric inpatient units for young people must be the preferred placement in most situations and suitable facilities must be urgently developed in NI (see para 3.13-3.16.)

They provide treatment based on a model of care which takes account of the developmental needs of the young person, but at times, those needs may be better met in adult services. [90] For example, those young people under the age of 18 who work, live independently from their family, are in partnerships, or are parenting children may find that adult services are more appropriate. Those approaching the age of 18 at the time of first onset of major mental illness e.g. psychosis may similarly find the resources of adult services better orientated to their needs. There are "special circumstances" where admission to an adult ward may be acceptable and an inflexible policy is to be regretted if in the absence of an age appropriate place it precludes a seriously ill young person from the inpatient care they need.

4.47 We also believe that the personal preference of a young person aged over 16 to be admitted to a local adult facility rather than a remote young people's psychiatric inpatient unit must be considered and respected wherever appropriate. Good practice guidance on admissions of young people to adult psychiatric wards is available [91] [92] and every effort should be made to achieve compliance with such guidance.

Community Services

4.48 There is a need to ensure that those in contact with children have knowledge of children's mental health needs, and know how to refer to the appropriate specialist services. Collaboration between education, CAMH professionals, and colleagues in the non-statutory sector is lacking and vital to the early identification of problems and to maximise the health outcomes of children.

Legal provision for Children

4.49 The main legislation underpinning CAMH services is the Children (Northern Ireland) Order 1995. Part I of that Order provides core principles for legal decision-making concerning children. In addition, the principles in the Order provide a solid framework for planning and delivering all children's services. Relatively few children and adolescents are made the subject of compulsory care and treatment under powers in the present Mental Health (Northern Ireland) Order 1986. Despite this, the Review considers that the ability to do so, when appropriate, is vital to the efective care of certain young people. The ability to provide the protection afforded by law to detained people and the inclusion of principles relating to consent by minors and restriction of children's liberty within the Code of Practice [93] is equally important.

4.50 The Review's Legal Issues Working Committee will report separately on a new legal framework. This will include principles for care and treatment of children and young people.

Involving Users and Carers

4.51 A clear intention of the Review was to engage consumer expertise as a means for testing out its ongoing work and proposals. The Review employed a range of consultation methods to elicit the views, opinions and advice of interested individuals and groups.

Within the CAMHS expert working group and its sub-committees, a range of stakeholders was represented. These included workers from statutory health, education and voluntary service backgrounds as well as representatives from service user/carer groups.

4.52 The benefits to health services of involving users and carers are well established.[94] The NHS Executive has detailed a range of such benefits including: increasing the likelihood that services are appropriate and effective, based on identified needs; meeting users' and carers' increasing wishes for more openness, accountability, and adequate information about their health condition, treatment and care; improving healthcare outcomes and client satisfaction; and providing access to reliable and relevant information that may help clients to assess clinical effectiveness for themselves.[95]

4.53 The Audit Commission's Report – Children in Mind[58] stated that CAMHS commissioners and service providers needed to take a holistic approach and assess needs systematically by consulting widely, including children and their parents. The need to involve children in service planning and evaluation has become clearer since the UK Government ratified the United Nations Convention on the Rights of the Child (UNCRC) and since the implementation of the Children (Northern Ireland) Order 1995.

4.54 Pressures placed on parents and carers when young people experience mental ill-health can be significant, and in Britain the requirement to engage with carers to assess and meet their needs has been established through the National Service Framework for Mental Health, Standard 6. In a broader sense the importance of engaging carers' expertise in helping to shape individual care plans and in contributing to service planning and evaluation is also widely recognised and methods for doing this have been described e.g. Carers Northern Ireland, 2000.[96] In view of these issues the case for involving service users and carers in the most significant review of CAMH services ever undertaken in NI was clear.

4.55 Consequently the Review commissioned a series of consultation exercises to explore service user and carer views. These involved a number of client groups including specific users of CAMH services, their carers, as well as targetted consultations with young people from ethnic minorities, children 'at risk' as well as representatives from young people in general. This focus on consultation provided a wealth of feedback and this material is available at www.rmhldni.gov.uk.

4.56 Of note was the specific exercise with CAMH services users and carers, whilst not an exhaustive or comprehensive investigation of user and carer views of services in the region it does provide a useful indication of the types of opinions and concerns that people hold based on real experiences of using services.

4.57 The investigation employed a 2 stage qualitative approach consisting of an open ended questionnaire and a series of 4 focus groups. Findings from the questionnaire study showed that to a large extent service users felt positive about their contact with CAMH services. Clearly the interpersonal contact and communication between users and providers is a strength of current provision. However, considerably more detail was captured through discussions with users and carers in the focus group study.

4.58 On the whole, participants in these discussions were more critical of services than were those who completed questionnaires. Some participants stated that they did not feel consulted or heard during their treatment or during the treatment of their children. The most common criticism voiced by many people was about the unacceptable length of time they found themselves waiting to be seen once they had been referred. A number of carers commented on the absence of specialist services such as for eating disorders or attachment difficulties. Difficulty with accessing respite was also a concern.

4.59 The issue of a lack of information provision and understanding about the role of CAMHS in the community was something highlighted in both questionnaire and focus group responses. Participants felt that CAMHS needs a higher profile to contribute to public understandings about mental health issues and to alert families who might benefit from the services. Many stated how they regretted not knowing what CAMHS had to offer sooner as they felt this delayed their receiving help for their children. Young people described how stigma affected their lives and could be an impediment to connecting with services.

4.60 One of the clearest lessons from the consultation is that carers as a group, as well as young people, have complex needs and sophisticated views about CAMHS. Research has indicated that professionals can hold confused views of carers, seeing them as resources or co-workers or clients or some combination of more than one of these roles. [97] The type of support offered will be shaped by these conceptualisations, but these complex issues are rarely taken into consideration when planning service development. Further detailed consultation with carer groups at local and regional levels would help to clarify carers' needs, what carers can bring to services and what might be the best ways of negotiating around these issues.

4.61 In addition the views of carers were also sought by offering various groups and individuals the opportunity to present verbally or in writing to the Committee. It was clear that the development of information for users, carers and other agencies explaining the range and scope of CAMH services was a priority.

4.62 As well as indicating satisfaction with many aspects of CAMH services, the users and carers consulted in the course of the CAMHS review highlighted much dissatisfaction and offered many suggestions about how their concerns might be addressed. The following are among the areas signposted for development:

- the need to prioritise developing service capacity at all tiers of provision to improve general accessibility, reduce unacceptable waiting times, and address limited or absent availability of specialist services to specific groups was emphasized by users and carers;

- it appears that there is a need to establish public health information projects with regard to child and adolescent mental health, and to improve information provision to communities about their local services;

- users and carers indicated willingness to work collaboratively with providers in terms of developing care and treatment plans and sharing information; models of treatment and service provision should be developed along lines that will facilitate such collaboration;

- there is a need to implement assessment models that evaluate the needs of carers and other family members as well as identified patients, and that utilise the expertise available within families about how help should be provided; and

- in terms of CAMHS outputs, user-focussed evaluation of services should be established as standard practice, to include investigation of their overall public health impact;

4.63 A next stage in this process of engagement may be a commitment to quantifying user concerns in areas highlighted by this consultation. Crucially, methods and organisational structures should be established to ensure user/carer involvement in the future shaping and monitoring of CAMHS.

Ethnic Minorities

4.64 The views of children from ethnic minorities were also of particular note. Lack of trust, and concerns about confidentiality, as well as language difficulties were all identified as barriers to children and young people seeking help and advice. The young people also emphasised the importance of their family circle and how it played a very significant role in the young person's life. Notably family was viewed as being both a cause of strain and a support.

4.65 Participants also felt that they were more likely to be bullied or teased because of their ethnic origin, and they felt that more needed to be done to enhance seem esteem. However there was mixed feelings about the provision of formal school based information etc on ethnicity as there was a fear that this would further identify them as different. The clear lesson from the consultation is that much more research is needed in collaboration with children and young people from an ethnic minority background.

Implementing the Vision

4.66 In order to realise the vision of a comprehensive CAMH service for Northern Ireland, the Review considers that a structured implementation process is required. Central to this process will be the CAMHS Development Co-ordinator who would work with an implementation Advisory Group comprised of commissioners, providers and users. The work of this group will be facilitated by a sub-committee structure which will address the following 4 areas:

- **Commissioning**. A sub-group, ideally short-lived, would address clarification and agreement of commissioning arrangements for CAMHS in Northern Ireland.

- **Informatics**. This sub-group would address issues such as the commissioning of a regional needs-assessment study, CAMHS mapping and the development of information systems.

- **Service delivery**. This group would focus on the implementation and further development of a service model for CAMHS, addressing such issues as establishing lead agencies and service delivery models for CAMHS tiers, developing managed clinical networks and, reviewing multi-disciplinary and multi-agency working.

- **Work-force develpment**. This group would address issues such as developing capacity throughout the tiered CAMH service and addressing the training and continuing professional development needs of service providers.

RECOMMENDATIONS

3. Providers should develop Children's Services Directorates bringing together all aspects of children's services as a single system under common management. *Para 4.4*

4. The Departments of Education and DHSSPS should set up an inter -departmental group to facilitate joined-up planning and commissioning of services in Mental Health and Education. *Para 4.6, 4.30*

5. Practitioners in education staff must be given training in the necessary skills and knowledge to address children's and young people's mental health needs, including fostering positive mental health in the classroom, and referring to more specialised staff when appropriate. *Para 4.8*

6. Managed networks, both local and regional should be developed across all CAMH services in Northern Ireland. A CAMHS Development Co-ordinator must be appointed to facilitate the development of these management structures. *Para 4.13, 4.16.*

7. Full time CAMHS managers should be recruited to cover populations of approximately 250 - 300,000. *Para 4.15*

8. A CAMH service mapping exercise should be carried out across all sectors by an independent research institute and repeated at regular intervals. *Para 4.21*

9. The 4 Tier model should be developed in Northern Ireland, re-emphasising the flexibility of the model as it was originally conceived. *Para 4.23*

10. A review of multi-disciplinary and multi-agency CAMHS working is required to inform the future planning and commissioning of services and should form an aspect of the early working brief of the CAMH Development Co-ordinator. *Para 4.37*

11. Community paediatric services and specialist CAMH services should develop clear referral pathways and guidelines for the assessment and treatment of ADHD and ASD. *Para 4.40*

12. CAMH services should ordinarily cover children and young people up to their 18th birthday. At all times they should be located in developmentally appropriate settings. *Para 4.9, 4.43,4.44, 4.46, 4.47*

13. The development of information for users, carers and other agencies explaining the range and scope of CAMH services is required. Methods and organizational structures should be established to ensure user/carer involvement in the future shaping and monitoring of CAMHS. *Para 4.61, 4.63*

CHAPTER 5

FUTURE SERVICES TO PROMOTE CHILD MENTAL HEALTH AND PREVENT MENTAL ILL-HEALTH

5.1 Mental health promotion can in part be understood as an approach to preventing the development of mental health disorders. Prevention has been understood in terms of 3 related types of activity. [98]

(i) Primary prevention aims to reduce the incidence of disorders by preventing new cases from developing. Primary prevention interventions are aimed at those who do not show any sign of disorder but may be at risk of developing disorder .

(ii) Secondary prevention aims to detect disorder early on and provide effective treatment. An aspect of such treatment is that it seeks out its recipients, as opposed to waiting for them to present.

(iii) Tertiary prevention aims to minimise the accruing disabilities or handicaps that may be associated with the presence of disorder.

5.2 Among the advantages of using this conceptualisation of mental ill-health prevention is that it demonstrates the continuity between 'prevention' and 'treatment', emphasising that prevention is future oriented. [99] Prevention is a core aspect of any comprehensive CAMH. The following are examples of some of the types of prevention work that need to receive significantly more attention within NI:

(i) Primary Prevention Strategies

5.3 Schools have a vital role to play in primary prevention work. There is strong international evidence to suggest that a whole school approach is vital in effectively promoting emotional and social competence and well being. The 'healthy school' approach, which has been promoted by the WHO, recognizes that it is the overall climate and context of the school that is supportive of development. This contrasts with programmes aimed only at the behaviour of individuals. The Personal, Social and Health Education/personal development curricula presents opportunities to promote the mental health and wellbeing of all children and young people at school across the primary, special and secondary school sectors in NI.

5.4 A number of more targeted programmes have been developed and shown to be effective in promoting emotional and social competence within a wider supportive environment. There is sound evidence from the literature that such work has a wide range of educational and social benefits including greater educational attainment and work success, improved behaviour, increased inclusion, improved learning, greater social cohesion and improvements to mental health. Moreover it seems that work, which aims to target particular groups of children or young people, has also a wider benefit for the whole school community. Schools that are effective with vulnerable groups, tend also to be effective schools.

5.5 Bullying can have a serious negative impact on individual children and young people even after a short period resulting in lost confidence and diminished self-esteem. Children who have experienced bullying are likely to have suffered loss of self-esteem, coping and resiliency and some may develop depression as a consequence of their experience. Effective appropriate early intervention is required to support the mental health needs of both the victim and the perpetrator. Strategies for the provision of services for children and young people who have experienced bullying and for the provision of assessment and treatment services for children and young people who display bullying should be considered.

5.6 In 1997, the British Medical Association produced a report that suggested that sex education should include information on homosexuality as part of the National Curriculum. This was based on the position that,

> *"Young lesbian, gay or bisexual people may be exposed to mental or physical health problems as a result of social isolation, bullying or lack of self-esteem"* [100]

5.7 The Review supports this suggestion recognising that delivery of such education must take into consideration the complexity arising from differing religious and societal influences on young people. The SHOUT Report [16] highlights the figures in relation to negative experiences of young people who identify as Gay, Lesbian or Bi-sexual (G.L.B). The findings of the Shout Report indicate that 24% of the respondents have been medicated for depression and 29% have attempted suicide and 26% have self-harmed. These figures correspond with figures for young G.L.B in Britain and America. The picture is emerging of serious issues of mental health for young G.L.B people. A cautious response is however required to ensure that young G.L.B people do not acquire another label of being mentally ill. Further investigation needs to take place into the specific mental health needs of young people who identify as gay lesbian or bisexual.

(ii) Secondary Prevention Strategies

5.8 Health promotion and other preventative strategies have been aimed at very young children (infants) and parent-infant relationships in particular and are often referred to as 'early intervention' or 'infant mental health' initiatives. In 'at risk' communities or families such interventions attempt to promote good parent-child relationships and should be more cost effective than trying to repair damage at a later stage. They may prevent the development of attachment disorders and other problems that are sometimes labelled as Attention Deficit Hyperactivity Disorder (ADHD). Health visitors have a vital role to play here and a focus on training in infant mental health, promotion of healthy attachments and accurate early detection of difficulties would greatly enhance their impact in this area.

5.9 a number of early intervention programmes have been developed and evaluated. Factors contributing to effective outcomes in early intervention include:

- multisystemic involvement including teacher training, an educational focussed component for the child and a supportive parent focussed activity;
- intervention beginning with very young children;
- intervention sustained over time; and
- community based intervention with partnerships between parents, the community and professionals.

The Incredible Years Programmes [101] is one such example of a well established and validated intervention which focuses on the behavioural problems of young children (2 - 8 years)

5.10 There is also a need for educational, health and mental health professionals to work in schools to provide early help for individual children who are beginning to show evidence of mental health difficulties. Independent Schools' Counselling services provide children and young people with a listening ear and someone to turn to in the school setting. These services provide accessible one to one support to vulnerable children and young people in coping with a range of issues that include domestic violence, bullying, parental alcohol abuse and family separation. Referrals are received directly from children and young people themselves as well as from parents and teachers. These services complement the work of the pastoral care team in school, fostering coping skills as well as a culture of accessing support among children and young people.

5.11 Homestart, and more specifically Sure Start, programmes are examples of such programmes, and may involve a range of Tier 1 professionals and trained volunteers. It is our conclusion however that the best programmes will take place across the tiers and will involve Tier 2 and 3 CAMH services for consultancy, evaluation and training. This will necessitate increased capacity at all these levels. Early intervention should not be thought of as purely a Tier 1 matter.

5.12 The development of infant mental health and early intervention services should be pursued as a preventative strategy throughout NI. The essence of such services is that they should be multiprofessional and multiagency, bringing together those working in the primary health field with Sure Start Workers, adult mental health services and CAMHS.

5.13 Tier 2 & 3 services are aimed mainly at behavioural problems that may present at home, in the school or both. Parent management training programmes have been shown to be the most effective method for intervening in behavioural problems in children. [10] Programmes which combine parent management training with problem solving skills training for children may be more effective than those programmes which only train the parents. [102] Therefore when parenting programmes are set up for established behavioural problems they should incorporate both of these elements. A strategy for the evaluation of these programmes should also be developed.

5.14 Experiencing mental ill-health can significantly interfere with parents' ability to make use of parent management programmes. Professionals should be aware that interagency working and possible onward referral to Adult Services might be required when parents have significant mental health needs. Equally interagency working is also required to protect and safeguard the welfare of children and young people in some cases of parental psychiatric illness. The recommendations of 'Patients as Parents' [103] are endorsed which highlight the need for education, training, audit and development of shared protocols to improve practice across this important interface. A video produced by the Royal College of Psychiatrists – "Being seen and heard" [104] explores this interface and is very useful for raising awareness and for training purposes.

5.15 Suicide and self-harm have been highlighted in this report as a pressing issue to be addressed by CAMHS. A suicide prevention strategy for NI is required and recommendations are made in the report of the Mental Health Promotion Expert Working Committee of the Review. The report is available at (www.rmhldni.gov.uk)

5.16 Risk factors for suicide have been identified at the individual, family and social-demographic levels. Among these, the presence of depression is the strongest health-related risk factor . Consequently it makes sense to orientate prevention work towards identifying and effectively treating young people with emotional disorders placing them at risk of suicide. Good follow up procedures after attempted suicide are also an essential component of CAMH service provision. A recent review has concluded, however , that "…child-focussed multi-modal programmes which include some combination of didactic instruction and discussion, bibliotherapy , and behavioural skills training may be very effective in increasing suicide-related knowledge, willingness to seek help if suicidal, and willingness to encourage potentially suicidal peers to see professional help." [105] Consequently there is a need to address the prevention of suicide through multi-modal programmes, probably best delivered via education services.

(iii) Tertiary Prevention Strategies

5.17 Children who have experienced child abuse, be it physical, sexual, emotional or neglect are likely to have complex physical, educational, social, psychological and protection needs. These needs require a multi-disciplinary, multi-agency response which addresses the needs of the whole child, and CAMH services at all 4Tiers have a role to play in helping children recover and ensuring that they are protected.

5.18 In addition, children with pre-existing mental health needs as well as those with physical and/or learning disabilities are likely to be at more risk of child abuse or repeat abuse. These children need effective services, which recognise the complexity and multiplicity of symptoms rather than treating symptoms in isolation. Services need to be delivered in a manner that avoids labelling and stigma. This labelling presents problems for some children particularly when their abuser may have given them messages that they were 'mental' or defective as part of the grooming/control process.

5.19 Children and young people who display sexually harmful behaviour also have complex mental health needs that need to be considered by a comprehensive CAMH service. The complex mental health needs of all children who have experienced abuse as victims or perpetrators should be addressed early to avoid likely presentation to adult mental health services later in life.

5.20 As such, strategies for the provision of post-abuse intervention services for children and young people, and for the provision of assessment and treatment services for children and young people who display sexually harmful behaviour, should be developed and implemented. These strategies may need to include the contribution of CAMHS and set out how treatment and protection services will be co-ordinated and integrated across disciplines and agencies.

5.21 The disturbingly high levels of mental ill-health among looked-after children have been mentioned elsewhere in this report. The limitations of both the social care and medical models as the basis of organising mental-health supports and interventions for looked-after children have been described.[106] Organising child mental-health services around a medical model approach – reliant on the presence of symptoms as the basis of referral – tends to result in multiple referrals for assessment and treatment once difficulties and symptoms have already emerged.

5.22 There is a clear need, when organising mental health services to LAC, to consider developmental processes, and the types and timing of interventions required to support these processes. Care providers need support from dedicated LAC mental health services organised along such lines to encourage the alignment of service contacts with key developmental stages, therefore providing more opportunity to support care providers and engage specialist mental-health workers in issues of prevention.

5.23 The needs of young people with autistic spectrum disorders have been referenced within this report. In particular the need to help young people develop their social and communication skills to minimise social exclusion and prevent the mental health difficulties that can result from such exclusion has been highlighted. Many CAMH services have provided social skills training for young people with ASD, yet evidence suggests that young people do not easily make links between what they do in social skills groups and real settings.[107] Within Craigavon and Banbridge Health and Social Services Trust, the Tier 3 CAMH team have developed partnerships with the Southern Education and Library Board's Youth Division and Craigavon Borough Council to provide social skills interventions linked with activities designed to promote social integration. The usefulness of such approaches has been demonstrated.[108] Wider application and evaluation would help determine the utility of such programmes in preventing the development of mental health difficulties.

Progressing prevention and mental health promotion

5.24 The need for public information campaigns with regard to child and adolescent mental health has been highlighted by the Review's CAMHS user/carer consultation. The need for a specific public health approach with regard to the impact of civil conflict has also been highlighted.

5.25 This could prove helpful, particularly in a society emerging from a period of protracted conflict, with many families still continuing to struggle to come to terms with the consequences of the events over the past 35 years.

5.26 Health promotion strategies could also incorporate training and education for CAMH staff regarding the impact of the 35 years of civil conflict on the population of NI. The need for this has been consistently highlighted in all Government consultation documents such as the Bloomfield Report etc [109] all relating to the needs of those affected by the conflict.

5.27 The benefits of promoting good mental health have been asserted in the report of the Review's expert working party on mental health promotion. The Review welcomes and endorses the recommendations in this report that will result in adequately resourced mental health promotion in NI and help realise the aspiration of effective health promotion as an essential component of a comprehensive CAMHS.

5.28 The development of a CAMH community psychology service to be delivered regionally via the CAMHS network is recommended. Community psychology as a discipline has emerged worldwide over a number of decades, but particularly in areas that have been affected by profound socio-political conflict such as North America during the period of the civil rights struggles or South Africa following the abolishing of apartheid. It provides contextual analysis that is cognisant of social issues and environmental stressors and supports mental health workers in orienting their activities towards a broader public health portfolio embracing advocacy, lobbying, community networking and mobilisation. [110]

5.29 A community psychology service would work with the regional health promotion service, locally based community development services, and other statutory and community partners. Its purpose would be to identify, develop and deliver in collaboration with local communities, projects that support those communities in increasing the emotional well-being and resilience of their young people and protect them from developing mental ill-health

5.30 In NI there are also legacies to the conflict, one such area causing much concern is the extent of the influence of paramilitary organisations and how many public housing areas have extensive paramilitary activity and control, causing many problems for local populations, particularly young men. During the last 5 years alone more than 9,500 families have been forced to move from their homes due to the impact of the civil conflict. [111]

RECOMMENDATIONS

14. Further investigation needs to take place into the specific mental health needs of young people who identify as gay, lesbian or bisexual. *Para 5.7*

15. Mental health promotion and prevention in the school setting should be developed across all schools, to include Independent School's Counselling services, the health promoting school, and pastoral care initiatives. *Para 5.10*

16. The development of infant mental health and early intervention services should be pursued as a preventative strategy throughout Northern Ireland. *Para 5.12*

17. Parenting programmes should be expanded and incorporate both parent management training with problem solving skills training for children. *Para 5.14*

18. A suicide prevention strategy for Northern Ireland is required. *Para 5.15*

19. Post-abuse intervention services for children and young people, and for children and young people who display sexually harmful behaviour , should be developed and implemented. *Para 5.19*

20. A CAMH community psychology service should be developed and delivered regionally through the CAMHS network *Para 5.28*

CHAPTER 6

FUTURE SERVICES TO THOSE WITH MENTAL ILL-HEALTH

In this Chapter detailed recommendations are provided which will go far to addr essing the gaps in current services identified within Chapter 3.

Carers and Family Members in CAMH Services

6.1 Accessing appropriate services for children and young people is a major issue for carers. While early intervention is widely recognised as highly beneficial, long waiting lists and lack of services mean that it is often impossible to put this into action.

6.2 Carers recognise the unacceptable nature of the admission of young people into adult units. Families sometimes feel excluded from and ill-informed about treatments being provided by CAMH Services. They would favour a co-operative approach, which includes families as equal partners in care and recognises their expertise with regard to the young person.

6.3 The emotional needs of carers need to be addressed, not least because responsibility for the ongoing care of a young person often falls heavily on family members after discharge. Support should be provided for parents and carers of young people admitted to inpatient units, both on an individual and group basis. Support for family members should include age-appropriate support and information for siblings and young carers.

6.4 Voluntary and community groups have an important role to play in supporting carers and parents of service users. The Valuing Carers Strategy Document [112] asserts that, "All carers should have access to local carer support services which we believe are best run and managed by the voluntary and community sector particularly when cares themselves are involved in the management arrangements".

6.5 Young carers of mentally ill parents have special needs and we support the recommendations in sections 5.89 – 5.91 of the Adult Mental Health Committee report [113] to be found at www.rmhldni.gov.uk.

Mental Health Inpatient Units

6.6 Comprehensive Tier 4 adolescent inpatient services must include both acute care inpatient provision which is able respond to emergency admissions of acutely disturbed or high risk young people with a mental disorder and medium to long-term planned therapeutic inpatient provision. Both types of adolescent inpatient places should be available for a given population. There must be close working links between the acute care and medium/long-term therapeutic inpatient provision and the capacity and flexibility for young people to move between the two as appropriate.

6.7 The number of inpatient places required for a given population must be based on a comprehensive, multi-agency needs assessment. This must take into account the known prevalence and incidence of mental health problems as well as local demographics including measures such as the child poverty index and multiple deprivation indexes for the area concerned. Local geography must also be taken into account when planning services.

6.8 Further expansion of inpatient provision after the current planned expansion is implemented should depend on a reassessment of need that should be multiagency and take into consideration the impact of the proposed regional specialist social/emotional/psychological unit.

Transition to Adult Mental Health Services

6.9 The transfer of care between child and adolescent services and adult services usually occurs around the age of 18. There may be circumstances when it is in an adolescent's best interests for a CAMH team to continue to care for them beyond the age of 18 while plans for transfer to adult services are put in place. Conversely, it may be appropriate to transfer some adolescents to the services for adults before their 18th birthday . Care pathways and protocols should be developed between adolescent and adult mental health services to allow optimal patient care during the transition from one service to the other. In all cases it is vital that collaborative arrangements between adult mental health services and CAMH services is put in place to ensure that the suffering in a child or parent does not go undetected or untreated

Early Intervention in Psychosis

6.10 There is a body of evidence which suggests that early intervention in psychosis, including both medication and psychotherapy approaches, is associated with better psychosocial functioning, both in the short term and at 20 year follow up. Mental health services to this group of young people should not only provide effective and appropriate interventions but also be sufficiently competent to work sensitively to address their distinctive needs and everyday culture. Early intervention teams specialising in working with young people aged between 14 and 25 who are experiencing their first episode of psychosis are one possible way of delivering services. They provide a range of services including antipsychotic medications and psychosocial interventions tailored to the needs of young people. They take an optimistic view of the person's ability to recover and eschew conventional preoccupation with symptom management and diagnosis. Such services need to be designed and delivered using a partnership approach involving CAMH, adult mental health, primary care, education, criminal justice users/carers and have yet to be developed in NI. [114]

6.11 There is a clear opportunity to link adolescent Tier 4 services with emerging services for early intervention in psychosis. The relationship with adult community mental health teams is vital in cases of older adolescents, particularly with the transition to adult mental health services. Some Tier 4 services in England are developing link posts with a specific remit to provide regular input into the local Tier 3 teams and adult community mental health team. Clear guidelines are needed in the absence of age appropriate and consistent mental health services for 16-19 year olds. The interface between CAMH services and adult mental health must be addressed and links established between Tier 4 specialist CAMH and adult community mental health teams as well as Tier 3 CAMH services. Collaborative working arrangements are essential. Separate age appropriate services geared towards early diagnosis and interventions should be developed. We refer readers to sections 4.51 – 4.56 and recommendation 42 of the Adult Mental Health Committee report.[113] This can be found at www.rmhldni.gov.uk.

6.12 Effective early intervention requires greater public awareness of Psychosis. The Adult Mental Health Committee have addressed this as a priority area for future services . [113]

Assertive Outreach

6.13 It is recognised that improvement in provision for children and young people at specialist Tier 2/3 CAMHS will impact positively and decrease the number of those requiring Tier 4 service. In other cases improved Tier 2/3 provision and closer links between Tier 3 and 4 will ensure that an interagency working approach and increased flexibility of service. This could help to facilitate movement of the young person through the tiers of CAMH service.

6.14 Assertive outreach provides frequent contact and co-ordinated intensive treatment with the young person and/or their carers by a multidisciplinary team. It could be delivered by collaboration between Tier 4 and Tier 3 services in conjunction with other agencies. It can take place in an inpatient setting or exclusively as an outpatient assertive outreach model, or in conjunction with day unit provision but day units are more readily applicable to urban populations than to scattered rural populations because of distances of travel involved in the latter case.

6.15 Intensive treatment can be developed as a result of collaboration between CAMHS and social services or education or both. This can be achieved through joint work between Tier 2/3 and Tier 4 CAMH or by collaboration between CAMH services and paediatrics, or CAMH services and adult mental health. In order to function effectively there needs to be close links with, and support from, adequately resourced Tier 2/3 specialist CAMH teams as well as age appropriate Tier 4 inpatient beds for children and adolescents. Models of assertive outreach/intensive treatment/day unit treatment for young people with complex needs should be developed and implemented by commissioners and providers as a priority.

Out of Hours and Emergency Services

6.16 No community CAMH service in NI can, within existing capacity, provide 24 hour cover to general hospital A&E departments. In some areas cover is provided by combinations of social services duty social workers for under 16s, and adult psychiatric services for over 16s in consultation with the limited numbers of CAMH consultant psychiatrists.

6.17 Although emergencies that relate to mental disorder in young people are relatively small in number all sectors should provide services that are able to respond to the needs of young people on the same day. Where residential or inpatient facilities are concerned, emergency cover by appropriate professional staff and/or managers at a number of levels must be available on a 24 hour-a-day basis.

6.18 The interface with the crisis response and home treatment initiative within the adult mental health report should be developed with the inclusion of the 16 – 18 age group in these services. Out of hours services should be developed to meet need while responding to the demands of the European Union (EU) Working Hours Directive.

Emergency Provision

6.19 Improved emergency provision in CAMH services will reduce Tier 4 demands. There should be improvements in emergency access to service Tier 2/3 provision and closer links between the Tier 4 services, will ensure interagency working and increased flexibility of service.

Learning Disability

6.20 A requirement that no child should be excluded from receiving a mental health service on the grounds of having a learning disability is key to meeting the principles of accessibility, non-discrimination and social inclusion. Specialised training and skills are required to provide effective mental health, educational and social assessments and interventions for a number of young people with a learning disability. These skills cannot be assumed and require training and suitable resources.

6.21 The Review's Learning Disability report [115] anticipates that 'mainstream services will take the lead for those with a mild and moderate learning disability with joint working for those with a more severe learning disability.' To achieve this mental health services are required for children and adolescents who have a learning disability at all Tiers.

6.22 No one particular service model is recommended but any model should be delivered by staff experienced in working with children & young people with learning disability and who also have training and expertise in specific mental health problems. Specialist CAMH services need to continue to develop close working relationships with the learning disability services.

6.23 Inclusive policies need to reflect partnership working between the education, social, and child mental health services and learning disability . There should be clarity in the local arrangements for future CAMH/learning disability services to ensure that a coordinated and integrated package of care is delivered.

6.24 Specialist mental health services for children and adolescents with learning disabilities should be commissioned as part of specialist mental health services for all children. A small number of key staff should be trained in both learning disability and mental health disciplines to lead development. Locally provision will depend on increased capacity of CAMH Services and any change must therefore be incremental. However it is recommended that future severe learning disability inpatient provision should be in a community-based child and adolescent specific units. Developed and more effective working relationships in the local arrangements for future CAMH/learning disability services should ensure that a co-ordinated and integrated package of care is delivered.

Autistic Spectrum Disorder Assessment and Treatment

6.25 The Review has produced a paper detailing recommendations for services to individuals with ASD. We endorse the recommendations made within this paper and in particular would wish to highlight the recommendation that a service manager in each Provider should have overall responsibility for the development and coordination of services for children and adults with ASD. It is agreed that creation of a separate programme of care would divert scarce resource from the development of direct service provision for those affected by ASD. We acknowledge the need for CAMH professionals to acquire greater knowledge and experience in assessment and diagnosis of ASD. All local area services will need to plan for increased levels of demand on already overstretched existing services. The following recommendations are consistent with the National Autistic Plan. [31]

6.26 A service is required specifically to assess children who are suspected to have ASD regardless of learning ability which can then provide follow up treatment, management, education and support and which will also support them in the transition to adulthood.

6.27 ASD services should be locally available, multi-agency and multidisciplinary including an educational specialist and a family support worker. Clinical and Care management should be across the broad children's service and come under the Children's Services Directorates recommended in paragraph 4.4 of this report. A senior manager within the Directorate should be responsible for co-ordination of ASD services for children. Community paediatric services may be the base service for early assessment and diagnosis but specialist CAMH input will be required for consultation, second opinions, joint-working and referral for treatment of mental health issues. Social care packages including the promotion of social skills and social integration will be necessary after diagnosis with a keyworker responsible for ensuring delivery of these services.

Looked After Children

6.28 Children looked after by social services in children's homes, foster homes and other residential placements often face complex and enduring interpersonal and mental health problems affecting every aspect of their lives and making it dificult for them to accept help and support and for staff and carers to maintain therapeutic relationships. This is especially so for older adolescents as they anticipate leaving care.

6.29 Social workers and mental health professionals have much to contribute to each other's practice in this area. Close collaboration between social services and CAMH services should be a cornerstone of LAC services.

6.30 The complex and long term needs of looked after children have consistently challenged the Trusts and community and voluntary service providers. Any intervention, plans or treatment is complicated by the reluctance of looked after children to attend formal therapeutic services. A range of service options needs to be developed to allow the intervention best suited to meet the young person's needs.

6.31 Those who deliver the services require support, training and high quality supervision and, in addition, consultation from specialist CAMHS professionals to enable purposeful intervention and to allow young people in public care to meet their full potential and make the most of their life opportunities.

6.32 Furthermore a model that prioritises and meets the needs of LAC throughout NI should be developed in consultation with social services and other professional groups working with LAC and their carers. Such development has already begun in some providers. However services should not be developed piecemeal, but should be developed equitably across NI.

6.33 Clinical aspects of LAC should include the liaison with and consultation to the network surrounding the child, comprehensive assessment of need, intervention with the child and carers, supervision and training, audit, research and evaluation.

Alcohol and Substance Misuse

6.34 Prevention and treatment strategies for alcohol and substance misuse problems in young people under 18 should be incorporated together in a co-ordinated, multi-agency and specific strategy for the long-term. The recommendations of the Alcohol and Substance Misuse report are supported in this regard. Details can be found in Chapter 8 of their report. www.rmhldni.gov.uk

Feeding and Eating disorders

6.35 The NSF for Mental Health [116] recommends that treatment of severe eating disorders be commissioned from specialist services.

6.36 NICE [117] emphasises that "most people with anorexia nervosa should be managed on an outpatient basis with psychological treatment provided by a service that is competent in giving that treatment and assessing the physical risk of people with eating disorders".They also state that "admission of children and adolescents with anorexia nervosa should be to age-appropriate facilities (with the potential for separate children and adolescent services), which have the capacity to provide appropriate educational and related activities." In practice this may involve a range of settings.

6.37 The NICAPS study [53] found that, in addition to an eating disorders diagnosis and the burden or care on family members, factors that contributed to inpatient admission included ease of access to services, clinical experience of the referrer , the range of alternative to inpatient care and the general backdrop of service organisation.

6.38 Children and adolescents with eating disorders should be cared for within CAMH services providing quality care. [118] However flexible arrangements where specialised adult eating disorder teams with CAMH professional input manage older adolescents are applicable in those aged 16 and above. Working relationships between paediatric, medical and psychiatry in-patient services should be developed for continuity of care.

6.39 The nature of service provision for feeding and eating disorders in NI needs to change with a particular increase in specialised outpatient services, and more specialist teams within generic settings, both inpatient and outpatient. Specialist outpatient services for feeding and eating disorders should be developed in NI.

Children that are victims of Trauma

6.40 The development and expansion of evidence based services to address psychological trauma in children should be taken forward as a priority The expertise gained in all sectors should inform the developments. Care pathways should include the contributions of Specialist CAMHS and Trauma Advisory Panels.

Services for Children and Adolescents with Challenging Behaviour

6.41 As with services for LAC, specialist community-based teams need to be developed or enhanced through training, support and access to consultation. There are some good examples of such teams working well in parts of NI; teams flexibly delivering 'outreach' services with an emphasis on community development. Further development of such services will necessitate some enhanced capacity at Tiers 2 and 3.

6.42 The ‘Children Matter’ Review [70] reported a need for a small children’s residential sector for children with emotional and psychological needs to support community and hospital services for adolescents. In other parts of the UK this is provided by the independent sector and such provision is almost nonexistent in NI. We support plans for a regional specialist social/emotional/psychological unit to complement acute psychiatric hospital provision.

Youth Justice and Forensic Services.

6.43 Mental health is a risk factor associated with offending. Specialist CAMH services should develop close working relationships and care pathways with the Youth Justice Teams. The NI strategy on young offenders calls for the effective attention to the mental health needs of young offenders, which will avoid them being inappropriately dealt within the youth justice system.

6.44 Preventing youth offending and re-offending requires a multi-agency approach. Delivery of effective programmes requires training in the specific intervention programmes and there is evidence that without quality assurance programmes they may not only fail to reduce re-offending but may actually increase it. [119]

6.45 A small number of children and adolescents present major challenges to services because of their pattern of extreme problems and/or the circumstances that they require for effective treatment. The work they require is disproportionate to their numbers and, in some cases, solutions to severe problems cannot be found at local or regional levels. A focus on analysing patient flow (patients journeys) and the design of appropriate care pathways are important matters for appropriate Research and Development (R&D). A regional forensic CAMH service should be developed in NI. The objective should be planned care, initiated at the local level, being the basis on which integrated services are delivered.

Ethnic Minorities

6.46 As outlined earlier in the report, the Review conducted a consultation exercise with a number of children and young people from an ethnic minority background. Whilst it provided some useful insight into the needs and requirements of this particular group it is clear that much more research is required, in partnership with them and their families. However some concrete recommendations can be drawn from their responses as to how CAMH services might best meet their needs. Firstly, in their service delivery strategy local CAMHS services should include plans to meet the mental health needs of children and adolescents and families from ethnic and other minority groups in their community .

6.47 Services that are culturally competent should be supported by individuals who have the skills to recognise and respect the language, behaviour, beliefs, customs, and characteristics of people from different ethnic backgrounds. Of particular note from the consultation with young people was a feeling of frustration that an interpreter was often required when they spoke with service providers. They urged CAMH to make a greater effort to recruit staff capable of speaking their native language.

6.48 A process of engagement with minority groups was clearly required and it is recommended that services should devise relevant strategies for communicating with local minority ethnic groups to inform them of the nature and range of services available and encourage them to access services.

Voluntary and Community Organisations and the statutory/non-statutory interface

6.49 Funding arrangements for voluntary and community agencies should be extended to a minimum of 3-5 years rather than on an annual basis. This would allow them to plan on a longer-term basis and facilitate their engagement as full partners with statutory agencies when developing CAMH services.

6.50 The extension of CAMH mapping exercises to the full breadth of voluntary and community as well as statutory services will allow evaluation of progress in addressing these needs. Statutory agencies should include the appropriate voluntary sector agencies as full partners when developing CAMH services.

Children with Sensory/Physical Disability and Enduring Physical Illnesses

6.51 Mental health services to children with physical and sensory disabilities and illnesses should continue to expand in support of regional paediatric specialties. Provision should be both regional and local. This is likely to require planning and commissioning on a regional basis and will require consideration when the specialist services are commissioned.

RECOMMENDATIONS

21. Support should be provided for parents and carers of young people admitted to inpatient units, both on an individual and group basis. Support for family members should include age-appropriate support and information for siblings and young carers. *Para 6.3*

22. The need for inpatient provision should be kept under continuing review . *Para 6.8*

23. The interface between CAMH services and adult mental health must be addressed and more effective collaborative arrangements established to ensure that the suffering in a child or parent does not go undetected or untreated. *Para 6.11*

24. Models of assertive outreach/intensive treatment/day unit treatment for young people with complex needs should be developed and implemented by commissioners and providers. *Para 6.15*

25. Out-of-hours services should be developed to meet need while responding to the demands of the European Union (EU) Working Hours Directive. *Para 6.18*

26. Specialist mental health services for children and adolescents with learning disabilities should be commissioned as part of specialist mental health services for all children. A small number of key staff should be trained in both learning disability and mental health disciplines to lead development. *Para 6.24*

27. Future severe learning disability inpatient provision should be in a community based child and adolescent specific unit. *Para 6.24*

28. A service is required specifically to assess children who are suspected to have ASD regardless of learning ability which can then provide follow up treatment, management, education and support and which will also support them in the transition to adulthood. *Para 6.26*

29. Clinical and care management for ASD should come under the Children's Services Directorates and a senior manager within the children's directorate should be responsible for co-ordination of ASD services. *Para 6.27*

30. A model that meets the needs of LAC needs to be developed. A cornerstone of the model must be close collaboration between social services and the network surrounding the child. Clinical aspects must include a comprehensive assessment of need, and appropriate evidence based interventions. *Para 6.29, 6.32, 6.33*

31. Prevention and treatment strategies for alcohol and substance misuse should be incorporated together in a co-ordinated, multi-agency and specific strategy for the long-term. *Para 6.34*

32. Flexible arrangements between CAMHS and specialised adult eating disorder teams, paediatric, medical and psychiatry inpatient services should be developed. Specialist child and adolescent outpatient services for feeding and eating disorders should also be developed in Northern Ireland. *Para 6.38, 6.39*

33. The development and expansion of evidence based services to address psychological trauma in children should be taken forward. The expertise gained in all sectors should inform the developments. Care pathways should include the contributions of Specialist CAMHs and Trauma Advisory Panels. *Para 6.40*

34. Specialist community based teams with an emphasis on outreach, service flexibility and community development should be developed for young people with perceived challenging behaviours. These teams need to work closely with other agencies and in particular need to be effectively integrated with specialist CAMH teams for support, training and access to consultation. *Para 6.41*

35. Specialist CAMH services should develop close working relationships and care pathways with the youth justice teams. *Para 6.43*

36. A regional forensic CAMH service should be developed in Northern Ireland. *Para 6.45*

37. In their service delivery strategy, local CAMHS services should include plans to meet the mental health needs of children, adolescents and families from ethnic and other minority groups in their community. This should include communication with these groups to inform them of services available and encourage them to access services when needed. *Para 6.46, 6.48*

38. Statutory agencies should include the appropriate voluntary sector agencies as full partners when developing CAMH services ensuring funding arrangements for these organisations are extended to a minimum of 3-5 years. *Para 6.49, 6.50*

39. Mental health services should be provided to children with physical and sensory disabilities and illnesses, in support of regional paediatric specialities. *Part 6.51*

CHAPTER 7

ENHANCING THE CAPACITY OF CAMH SERVICES

“This service is vital to the community, many people have benefited from this. This clinic should expand as there is such a big demand from it. More staff.”- *Parent/carer’s comment.*

“We had to wait a long time to be seen. I would say more staf and also more financial resources.”- *Parent/carer’s comment.*

This Chapter provides recommendations for enhancing the capacity of services. It includes detailed proposals on the development of an enhanced CAMH workforce, as well as more effective methods of information technology and financial resource management.

Current Budgetary Situation

7.1 It is difficult to find out what resources are allocated to CAMH Services in NI. O’Rawe [74] has shown that the available regional hospital activity information upon which presumably the strategy for equity investment is based, fails to comprehensively represent CAMH outpatient activity both in pattern and volume. She has ascertained that although children under 17 years represent 27% of the population, the proportion of expenditure on NI CAMH Services represents less than 5% of the total NI mental health budget. She also points out that the location of CAMH services within the overall programme of care model upon which the Regional Capitation Formula is predicated is not immediately apparent. Budgetary arrangements for CAMH services are not sufficiently clear and increased allocation of resources in proportion to need in order to support CAMH services in NI is urgently required. It is recommended therefore that CAMH services should have their own identifiable budget.

Information Management

7.2 Although a vast amount of data on the health of children is gathered within computerised health information systems in general practice, and hospital and community child health, very little is gathered on child mental health specific problems. There are difficulties with regard to confidentiality and also terminology in relation to mental health problems. Currently there are no agreed universal terms, definitions and indices of severity for use across disciplines and agencies for conditions such as autistic spectrum disorder, depression, and specific learning difficulties. Sharing information about LAC and those at risk of abuse is a significant challenge both in terms of practical difficulties in keeping the information up to date on this frequently mobile population and also in terms of confidentiality and data protection. An understanding of the background of health and social concerns as well as the current situation of the child is vital to the successful planning of the way forward. A robust information technology system such as PCIS should underpin the work of CAMH services. The Strategic Framework for Adult Mental Health Services [113] (paragraphs 7.7-7.15) recommends a regional information strategy for mental health and we recommend that this includes CAMH.

7.3 Adequate administrative support is essential to facilitate gathering of data and although administrative support to CAMH services in NI varies considerably between services it is too often insufficient. This impinges on data gathering and outcome measurement.

Workforce

7.4 Achieving the goals of this review and improving the mental health of children depend on the development of the professional workforce. This includes planned expansion of both the capabilities of current staff and their numbers.

7.5 Currently within NI existing staffing levels do not even meet present requirements. Vacancies exist in all disciplines. Limited career pathways with underdeveloped supervision and the high clinical demands hinder the recruitment and retention of staff across NI. There needs to be a sustained drive to increase both the number of training places and the number of such posts across NI. This will even out the present patchy provision of services and help to make careers more rewarding. In turn, this should promote recruitment and retention and create a virtuous circle. There is an urgent need for the delivery of a workforce plan for all disciplines involved in CAMH services.

7.6 There are a number of key drivers for the development of modern mental health services across both community and hospital. Service user expectations of standards of service have been raised through the increased use of advocacy services together with generally a louder voice for service user groups. The National Strategy for Carers [120] places additional demands on staff to ensure the wider needs of the family are also addressed. The carer's education and support programmes piloted in partnership with Rethink, the Sainsbury Centre for Mental Health and local trusts serves to demonstrate how this area can be further developed.

7.7 From the perspective of clinical and social care governance as highlighted in Best Practice Best Care [28] a statutory duty of quality has now been placed on Chief Executives across the HPSS system, issues such as risk management and health and safety are receiving due prominence. Staff are more focused on improving standards of care through the application of evidence informed practice that makes best use of resources and ultimately generates better experiences and outcomes for service users.

7.8 Whilst recognising the obvious advantages of modern atypical anti-psychotic medications with much reduced side effect profiles, there is adversely (due principally to less sedating properties of the drugs) an increased demand on nursing staff to support service users through the most acute phases of their illness in a safe and secure environment with an increased emphasis on therapeutic intervention. This also generates increased demand for 1:1 supervision within acute admission and psychiatric intensive care units, which significantly impacts on existing manpower resources. Preparatory training for enhanced specialist practitioners is therefore urgently required.

7.9 Clinical supervision is an integral component in the maintenance of professional standards, however current staffing complements pre-date the emergence of clinical supervision for nurses. Unlike other professional colleagues, who have time incorporated into their work programmes to facilitate supervision, nurses attempt to fit supervision around many other commitments. Within the DHSSPS best practice guidelines [121] it is argued that clinical supervision is essential in the provision of safe and accountable practice. There is obviously a significant workforce challenge in taking forward these guidelines.

7.10 The pattern of training and the qualifications held by social workers employed in CAMHS across the tiers reflects the diversity of service. They generally hold a recognised social work qualification and some also hold other relevant qualifications, for example in counselling, child protection, family therapy, mental health social work and play therapy. Practitioner posts at senior and principal levels should be developed at Tiers 2 - 4.

7.11 Awareness and foundation training in child and adolescent mental health issues should be incorporated into undergraduate training specifically in the following areas;

- Occupational therapy;
- Speech therapy;
- Family therapy;
- Play therapy;
- Art therapy, Music therapy; and
- Drama therapy.

This must be complemented by accessible post graduate training programmes.

7.12 In the management of service users with very complex conditions, e.g. ASD / Asperger's Syndrome, all staff may work across a number of sectors which includes private, independent, voluntary and other statutory partners such as Education & Library Boards. Isolated examples exist where models of excellence are being developed which require dedicated funding to ensure that all CAMH professionals have the necessary knowledge, skills and expertise to provide high quality care within these dynamic environments.

7.13 It is clear that service development plans in the future will dictate the development of a workforce sufficient to address all of the following areas:

- Eating Disorder;
- Alcohol and Substance Misuse;
- Forensic;
- Looked After Children;
- Autistic Spectrum Disorder (ASD);
- First Episode Psychosis; and
- Learning Disabilities.

Further work is required to explore these areas. The DHSSPS should establish small working groups to address the specific service development of service and training needs for these specific areas.

A small number of other issues that impact more indirectly include:

- the integration of the principles of Investing for Health in all aspects of service delivery;
- the GMS contract and the evolution of new roles for nursing within;
- primary care e.g. out of hours services;
- the European Working Time Directive,
- the new consultant contract;
- the role of the nurse consultant; and
- the review of public administration.

7.14 There is a clear need to consider the role of primary care and the function of primary care professionals in relationship to CAMH services. Early and accurate intervention is proven as key to good services. It is vital to get Tier 1 right. The tendency to immediately refer all children with mental or emotional difficulties to the specialist elements of the HPSS is both dangerous and wasteful. It leads to congestion of health services and may miss children with serious need, but whose problems cause fewer burdens to be experienced by adults around them. It often forces inappropriate referrals to Tiers 2, 3 or 4 so that they in turn have their effectiveness blunted. For families, another risk of inappropriate referrals, due to gaps at Tier 1, is otherwise avoidable stigmatisation.

7.15 One response recommended by the HAS was the development of Primary Mental Health (PMH) worker posts. These posts could be by professionals from any discipline with training and expertise in CAMH services and their role includes: [1]

- consolidating the skills of primary care and supporting education regarding CAMH services;
- aiding recognition of CAMH disorders and referral on; and
- assessing and treating some individuals with mental health problems who were considered appropriate for management at Tier 1 and Tier 2.

7.16 A Department of Health Review on PMH [122] workers concluded, “the development of CAMH services in primary care seems to be highly dependent on the new PMH worker posts”. It noted that 33.3% of providers surveyed had developed such posts and a further 25% had plans to do so.

7.17 In England and Wales there are up to 700 PMH workers in post and the National Service Framework [30] identifies that by 2006 all CAMH Service teams will have 5 such posts. This development has been patchy in NI, some providers are aiming at the continued development of the Tier 1 and Tier 2 services that contribute to CAMH services.

7.18 For NI, with a bigger child population and greater deprivation indices and the civil conflict factor, higher staffing levels will be required. In NI the percentage of children in the population (27%) is greater than the percentage in England (22%) by a factor of 1.2. It is difficult to calculate a weighting for deprivation and civil conflict but it is estimated that for NI an equivalent number of PMH workers associated with each CAMH team would be 6. It is recommended that the role and complement of PMH workers be expanded within NI.

7.19 At Tier 3 a critical mass of staffing is required for services to be safe, timely and effective and able to respond to a wide range of demands from specialist multidisciplinary assessment and treatment, to specialist consultation and liaison, teaching and training, research and audit and finally to support and provide consultation in primary care.

7.20 The precise level of staffing will vary according to indices of deprivation, urban and rural differences, the number of local partnerships required and teaching responsibilities. As services take on new responsibilities additional staffing will be required locally . Where services have a critical mass of staffing they are able to offer a greater range of community outreach services.

7.21 The NSF [30] has estimated that in England a generic specialist multidisciplinary CAMH service Tier 2/3 team with teaching responsibilities providing evidence based interventions for 0-17 year olds would require a minimum of 20 whole time equivalents (WTEs) per 100,000 total population and a non teaching service, a minimum of 15 WTEs. These figures are backed up by the work of Kelvin [123] who calculated similar figures based on a service specification model to enable evidence based service development in keeping with good clinical governance. The NSF points out that these figures do not allow for dedicated staff time from Tier 2/3 services to services such as Sure Start, looked after children teams, or youth justice teams and would not necessarily be sufficient to provide specialist services like a day unit. It also states that these figures do not reflect demographic variations. Thus using as a minimum the factor of 1.2 already referred to above we estimate that in NI specialist CAMH teams would be needed of 25 and 20 WTEs respectively. For this reason additional revenue funding should be provided on an incremental basis to ensure that a workforce is developed in sufficient numbers to provide the range of services required within the 4 tier model in CAMH services in NI.

7.22 It is worth emphasizing the importance of an attractive working environment for professionals and with this in mind considers that links between operational services and academic institutions should be developed and strengthened. The existence of such a mutual support system is a powerful recruitment tool. To enhance recruitment and retention, career paths should be developed for all professionals, inclusive of new role developments in CAMH services.

Education, Training and Research

7.23 The above profile illustrates that the existing provision for CAMH services is inadequate and unsatisfactory. The lack of capacity has led to pressure on existing services. Despite many examples of good practice the overall quality consistent and accessibility has suffered to the extent that urgent strategic action is needed to tackle the services and work force shortages in NI.

7.24 Insufficient numbers are being trained to meet health and social services needs let alone other initiatives. Training programmes at all tiers for all disciplines are not yet fully developed in NI. Universities, FE colleges, and in service training providers should develop the range of educational and practice development opportunities required to equip a variety of mental health practitioners with the knowledge necessary to develop the competencies for their work with children and their families.

7.25 Important research is going on for example in epidemiology, basic sciences and social services based at the Centre for Child Care Research at Queens' University. There has been collaboration between mental health specialists and social work academics. Such partnerships often generate significant synergy and enhance the capacity of each party. Nonetheless opportunities for participating in research that relates to child and adolescent mental health are limited in NI. To foster a local climate of research and critical enquiry, academic posts from the range of professions involved in CAMH service should be developed.

7.26 Governance and quality mechanisms in CAMH services should be further developed and implemented across NI.

Psychotherapy Services

7.27 Relationships within the family may contribute to or compound the mental health problems of children and the systemic training of a family therapist has a key role in CAMH services. Systemic Family Therapy is a method of conceptualising difficulties/problems within the context in which they occur. It is based on the idea that the behaviour of individuals and families is influenced and maintained by the ways other individuals and systems interact with them. It involves engaging the whole family system as a functioning unit and also embraces smaller systems (including individual work) and bigger systems than 'the family'. Carr's meta-analysis [124] found that for child focused problems, family therapy and systemic consultation was an effective treatment either alone or as part of a multi-modal or multisystemic treatment programme in child abuse and neglect, conduct problems, emotional problems and psychosomatic problems.

7.28 The specialist contribution which a child psychotherapist makes to CAMH services is the assessment and psychotherapeutic treatment of children adolescents and their parents based on psychodynamic concepts and application of related clinical techniques." Other functions of both family and individual psychotherapists in CAMHS include consultation to other professions and agencies.

7.29 The psychotherapeutic approach should be more strongly integrated into CAMH services in NI. There are very few dedicated family therapist and child psychotherapist posts in CAMH services in NI and the role of these disciplines should be further developed and enhanced.

Speech and Language Services.

7.30 Speech communication and language skills are essential for developing relationships, understanding social contexts and behaviour and expressing individuality. Children and young people with severe speech communication and language needs (SCLN) often present with marked emotional and behavioural difficulties and clinical depression.

7.31 Estimates of the incidence of SCLN vary. Estimates range from 3% to 20% of the school population presenting with some need, with the figure of 10% commonly accepted by academics and policy makers as the percentage of children with SCLN.

7.32 Although more detailed local demographic information is needed on the number of young people with Speech and Language difficulties and associated mental health difficulties, it is now recognised that many conditions resulting in communication disability in children and young people also have associated mental health issues i.e. brain injury, mild/moderate learning difficulties, dysfluency, ASD and ADHD.

7.33 The current availability of Speech and Language Therapy (SLT) provision to children and adolescents with mental health difficulties is not meeting existing requirements. Service development has evolved in patches within the NHS. Some regions within the UK now have a well established SLT service for people with mental health needs.

7.34 The role that speech and language therapists (SLTs) play within CAMH services should be recognised. SLT services should be adequately planned and resourced, based on local demography and need.

Occupational Therapy Services

7.35 Occupational Therapists hold a unique, key role in CAMH services, working across the age range and within various settings that offer mental health services to children and young people. This role was recognised within the HAS[1] document where occupational therapists were identified as one of the core professions that offer services within child and adolescent mental health.

7.36 Occupational therapists are the only health care profession with core skills and expertise in analysis, assessment, treatment and evaluation of occupational dysfunction that is contributing or consequent to psychological problems.[125]

7.37 Occupational therapists bring specialist rehabilitation expertise to multidisciplinary CAMH teams, which enables the child or young person to access meaningful occupation, by developing confidence and skills in occupations in the areas of productivity, self care and leisure.[126]

7.38 "Standards for Child and Adolescent Mental Health Services" [127] recommends that multidisciplinary resources are comprised of a range of disciplines inclusive of occupational therapists. Currently there are no occupational therapists in the CAMH services workforce in NI.

7.39 This gap in service provision in CAMH services needs to be addressed with occupational therapy representation being a core element of CAMH provision and service and workforce planning in NI. [128]

Clinical and Social Care Governance

7.40 Clinical and social care governance has been adopted by health services as a way of integrating financial control, service performance and clinical quality [129] and is the framework whereby service providers take corporate responsibility for the quality of the service delivered. Clinical and social care governance therefore forms the overarching principle of the management of good quality CAMH Services, with the central expectation of an adequately trained workforce, involved in continued professional development, and of sufficient size and diversity to meet the needs of the population served.

7.41 This Review welcomes and endorses the framework of clinical and social care governance. Throughout the Review reference will be made to the principles and tools of clinical and social care governance, such as service development, benchmarking, standard setting, effective management, risk management, user and carer involvement, evidence based practice, audit and research.

7.42 There is a recognition that much work has to be done to achieve the objectives of clinical governance to provide locally delivered high quality CAMH services across the 4Tiers and throughout NI. However it is important to note that as clinical governance risk assessment procedures begin to examine the adequacy of service infrastructure, capacity issues in CAMH services may become more pronounced.

RECOMMENDATIONS

40. CAMH services should have their own identifiable budget. *Para 7.1*

41. A robust information technology system such as PCIS should underpin the work of CAMH services. *Para 7.2*

42. Small working groups should be established to address the specific service developments and training needs for Eating Disorders, Alcohol and substance misuse, Forensic, LAC, ASD, First episode psychosis and Learning disabilities. *Para 7.13*

43. The role and complement of Primary Mental Health (PMH) workers be expanded within Northern Ireland. *Para 7.18*

44. Additional revenue funding should be provided on an incremental basis to ensure that a workforce is developed to provide the range of services requested within the 4 Tier model in CAMH services in Northern Ireland. *Para 7.21*

45. To enhance recruitment and retention, career paths should be developed for all professionals inclusive of new role developments in CAMH services. *Para 7.22*

46. Universities, FE colleges, and in service training providers should develop the range of educational and practice development opportunities required to equip a variety of mental health practitioners with the knowledge necessary to develop the competencies for their work with children and their families. *Para 7.24*

47. To foster a local climate of research and critical enquiry , academic posts from the range of professions involved in CAMH service should be developed. *Para 7.25*

48. Governance and quality mechanisms in CAMH services should be further developed and implemented across NI. *Para 7.26*

49. The number and role of family therapist and child psychotherapist posts in CAMH services should be enhanced and further developed. *Para 7.29*

50. The role that speech and language therapists (SLTs) play within CAMH services should be recognised. SLT services should be adequately planned and resourced, based on local demography and need. *Para 7.34*

51. Occupational therapy services should be developed as a core element of CAMH provision. *Para 7.39*

RECOMMENDATIONS

"I look back to what it was like last year or the year before…you kind of notice what a big change it can make" - *Parental comment*.

1. The development of a comprehensive CAMH service should be facilitated by establishing a structured implementation process and, addressed across health, social services, education, and youth justice. It should include a process for identifying public health needs of children with mental health problems. *Para 3.66, 3.67, 4.66*

2. A study of the mental health needs of children in Northern Ireland should be commissioned as soon as possible. *Para 3.68*

3. Providers should develop Children's Services Directorates bringing together all aspects of children's services as a single system under common management. *Para 4.4*

4. The Department of Education and DHSSPS should set up an inter-departmental group to facilitate joined-up planning and commissioning of services in mental health and education. *Para 4.6, 4.30*

5. Practitioners in education must be given training in the necessary skills and knowledge to address children's and young people's mental health needs, including fostering positive mental health in the classroom, and referring to more specialised staff when appropriate. *Para 4.8*

6. Managed networks, both local and regional should be developed across all CAMH services in NI. A CAMH development co-ordinator must be appointed to facilitate the development of these management structures. *Para 4.13, 4.16.*

7. Full time CAMHS managers should be recruited to cover populations of approximately 250 - 300,000. *Para 4.15*

8. A CAMH service mapping exercise should be carried out across all sectors by an independent research institute, and repeated at regular intervals. *Para 4.21*

9. The 4 Tier model should be developed in NI, re-emphasising the flexibility of the model as it was originally conceived. *Para 4.23*

10. A review of multi-disciplinary and multi-agency CAMHS working is required to inform the future planning and commissioning of services and should form an aspect of the early working brief of the CAMH Development Co-ordinator. *Para 4.37*

11. Community paediatric services and specialist CAMH services should develop clear referral pathways and guidelines for the assessment and treatment of ADHD and ASD. *Para 4.40*

12. CAMH services should ordinarily cover children and young people up to their 18th birthday. At all times they should be located in developmentally appropriate settings. *Para 4.9, 4.41 – 4.47*

13. The development of information for users, carers and other agencies explaining the range and scope of CAMH services is required. Methods and organizational structures should be established to ensure user/carer involvement in the future shaping and monitoring of CAMHS. *Para 4.61, 4.63*

14. Further investigation needs to take place into the specific mental health needs of young people who identify as gay, lesbian or bisexual. *Para 5.7*

15. Mental health promotion and prevention in the school setting should be developed across all schools to include Independent School's Counselling services, the health promoting school and pastoral care initiatives. *Para 5.10*

16. The development of infant mental health and early intervention services should be pursued as a preventative strategy throughout NI. *Para 5.12*

17. Parenting programmes should be expanded and incorporate both parent management training with problem solving skills training for children. *Para 5.13*

18. A suicide prevention strategy for NI is required. *Para 5.15*

19. Intervention services for children and young people that have suffered abuse and for children and young people who display sexually harmful behaviour, should be developed and implemented. *Para 5.19*

20. A CAMH community psychology service should be developed and delivered regionally via the CAMHS network. *Para 5.28*

21. Support should be provided for parents and carers of young people admitted to inpatient units, both on an individual and group basis. Support for family members should include age-appropriate support and information for siblings and young carers. *Para 6.3*

22. The need for inpatient provision should be kept under continuing Review. *Para 6.8*

23. The interface between CAMH services and adult mental health must be addressed and more effective collaborative arrangements established to ensure that the suffering in a child or parent does not go undetected or untreated. *Para 6.11*

24. Models of assertive outreach/intensive treatment/day unit treatment for young people with complex needs should be developed and implemented by commissioners and providers. *Para 6.15*

25. Out of hours services should be developed to meet need while responding to the demands of the European Union (EU) Working Hours Directive. *Para 6.18*

26. Specialist mental health services for children and adolescents with learning disabilities should be commissioned as part of specialist mental health services for all children. A small number of key staff should be trained in both learning disability and mental health disciplines to lead development. *Para 6.24*

27. Future severe learning disability inpatient provision should be in a community based child and adolescent specific unit. *Para 6.24*

28. A service is required specifically to assess children who are suspected to have ASD regardless of learning ability which can then provide follow up treatment, management, education and support and which will also support them in the transition to adulthood *Para 6.26*

29. Clinical and care management for ASD should come under the Children's Services Directorates and a senior manager within the children's directorate should be responsible for co-ordination of ASD services. *Para 6.27*

30. A model that meets the needs of LAC needs to be developed. A cornerstone of the model must be close collaboration between social services and the network surrounding the child. Clinical aspects must include a comprehensive assessment of need, and appropriate evidence based interventions. *Para 6.29 – 6.33*

31. Prevention and treatment strategies for alcohol and substance misuse should be incorporated together in a co-ordinated, multi-agency and specific strategy for the long-term. *Para 6.34*

32. Flexible arrangements between CAMHS and specialised adult eating disorder teams, paediatric, medical and psychiatry in-patient services should be developed. Specialist child and adolescent outpatient services for feeding and eating disorders should also be developed in NI. *Para 6.38, 6.39*

33. The development and expansion of evidence based services to address psychological trauma in children should be taken forward. The expertise gained in all sectors should inform the developments. Care pathways should include the contributions of Specialist CAMH and Trauma Advisory Panels. *Para 6.40*

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38. Statutory agencies should include the appropriate voluntary sector agencies as full partners when developing CAMH services ensuring funding arrangements for these organisations are extended to a minimum of 3-5 years. *Para 6.49, 6.50*

39. Mental health services should be provided to children with physical and sensory disabilities and illnesses, in support of regional paediatric specialities. *Para 6.51*

40. CAMH services should have their own identifiable budget. *Para 7.1*

41. A robust information technology system such as PCIS should underpin the work of CAMH services. *Para 7.2*

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43. The role and complement of PMH workers should be expanded within Northern Ireland. *Para 7.18*

44. Additional revenue funding should be provided on an incremental basis to ensure that a workforce is developed to provide the range of services needed within the four -tier model in CAMH services in NI. *Para 7.21*

45. To enhance recruitment and retention career paths should be developed for all professionals inclusive of new role developments in CAMH services. *Para 7.22*

46. Universities, FE colleges, and in service training providers should develop the range of educational and practice development opportunities required to equip a variety of mental health practitioners with the knowledge necessary to develop the competencies for their work with children and their families. *Para 7.24*

47. To foster a local climate of research and critical enquiry academic posts from the range of professions involved in CAMH service should be developed. *Para 7.25*

48. Governance and quality mechanisms in CAMH services should be further developed and implemented across NI. *Para 7.26*

49. Family therapist and child psychotherapist posts in CAMH services in NI and the role of these disciplines should be enhanced and further developed. *Para 7.29*

50. The role that speech and language therapists (SLTs) play within CAMH services should be recognised. SL T services should be adequately planned and resourced, based on local demography and need. *Para 7.34*

51. Occupational therapy services should be developed as a core element of CAMH provision. *Para 7.39*

ANNEXE 1

WHAT IS THE BAMFORD REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY

Introduction

1.1 In October 2002 the Department of Health, Social Services and Public Safety (DHSSPS) commissioned an independent review of law, policy and service provision affecting people with mental health needs or learning disabilities. The main factors influencing the decision to establish the Review were:

- recent reviews of mental health legislation in neighbouring jurisdictions;
- the need to ensure that law, policy and practice is in keeping with human rights and equality law; and
- the need to reflect current evidence of best practice.

1.2 An overall Steering Committee, whose terms of reference are shown atAnnexe 2, manages the Review. They are guided by inputs from Expert Working Committees, each of which is examining a particular area:

- Child and Adolescent Mental Health
- Learning Disability
- Adult Mental Health
- Forensic Issues
- Dementia and Mental Health Issues of Older People
- Social Justice and Citizenship
- Mental Health Promotion
- Needs and Resources
- Legal Issues
- Alcohol and Substance Misuse

The Review is also working closely with DHSSPS on a workforce planning group on mental health and learning disability services.

1.3 The Working Committee tasked with taking forward the review of CAMH Services (membership at Annexe 4) recognise that mental health problems and mental disorders in young people can devastate the lives of those affected and destroy the quality of life of those around them. Of specific significance in NI has been the emerging awareness of the impact of "Troubles related trauma" and the manifestations of sectarianism and associated violence within children and young people.

1.4 Society pays a high price in terms of social disruption, education failure, ill health, anti-social behaviour and hard cash for the failure to tackle these problems effectively. Links between childhood disorders and adult mental health problems are now well established.

Failure to break this pattern can result in generation after generation suffering from social exclusion with its attendant problems.

1.5. The Working Committee acknowledges that the effectiveness of certain interventions is proven both in terms of restoring damaged young people to full health, social potential and educational achievement, and in terms of savings on expenditure by society on later, more expensive treatments and interventions by a multitude of agencies. Perhaps most importantly of all, the Working Committee came to the conclusion that no one agency can tackle the problems on its own.

ANNEXE 2

TERMS OF REFERENCE

1. To carry out an independent review of the effectiveness of current policy and service provision relating to mental health and learning disability, and of the Mental Health (Northern Ireland) Order 1986.

2. To take into account:

   - the need to recognise, preserve, promote and enhance the personal dignity of people with mental health needs or a learning disability and their carers;
   - the need to promote positive mental health in society;
   - relevant legislative and other requirements, particularly relating to human rights, discrimination and equality of opportunity;
   - evidence - based best practice developments in assessment, treatment and care regionally, nationally and internationally;
   - the need for collaborative working among all relevant stakeholders both within and outside the health and personal social services sector;
   - the need for comprehensive assessment, treatment and care for people with a mental health need or a learning disability who have offended or are at risk of offending; and
   - issues relating to incapacity.

3. To make recommendations regarding future policy, strategy, service priorities and legislation, to reflect the needs of users and carers.

ANNEXE 3

THE CAMH REVIEW PROCESS

How did we involve people in developing the vision for the Child and Adolescent Mental Health Review?

1. The approach to developing the vision took account of Government Policies, the views of children and their families as well as professionals in both statuary and voluntary organisations. This information was gathered through extensive consultation and research from October 2003 to December 2004.

2. The CAMH review is a result of information generated through consultations, research, and good practice initiatives from October 2003 to March 2006. These included;

   - the establishment of the CAMH committee that managed the Review; and
   - the establishment of three working groups to review specific elements of CAMH service provision identified as;

     - Tier 1/2 services working group;
     - Tier 3/4 services working group; and
     - Psychological and Social Wellbeing working group

   - the organisation of a range of events to give all stakeholders the opportunity to present information to the CAMH committee: People and organisations were invited to give information to the committee in keeping with the Reviews terms of reference, with the specific emphasises on the needs of children, adolescents and their families;
   - additional people and organisations made submissions and presentations to the committee;
   - a content analysis of all presentations and submissions was completed;
   - workshops were held to explore issues regarding education, mental health promotion, adult mental health, alcohol and substance misuse, forensics, learning disability, social justice and citizenship;
   - user and Carer consultations were conducted utilizing both survey and focus group methodologies;
   - a critique of national and international service models was commissioned;
   - a meeting took place with the carer reference group within the Review;
   - a province wide review of service provision took place;
   - three newsletters were circulated to disseminate the work of the committee;
   - many members of the public and professionals making comments to and asking questions of the committee accessed a free phone line;
   - meetings were held with relevant people in the province; and
   - letters were received from many members of the public and professionals addressing the committee with issues and concerns regarding CAMH services.

ANNEXE 4

COMMITTEE MEMBERS LIST

Ms Moira Davren
Convenor – CAMH Committee

Professor David Bamford
Former Chair of the Review of Mental Health & Learning Disability

Dr Noel McCune
Consultant Child and Adolescent Psychiatrist

Dr Tom Teggart
Consultant Clinical Psychologist

Mr Stephen Dornan
Children Services Manager

Mr Maurice Devine
Thompson House Hospital

Ms Stephanie Wilson
Primary Mental Health Practitioner

Ms Jackie Nelson
Senior Clinical Nurse Specialist/
Clinical Nurse Manager, CAMHS

Ms Brenda Byrne
Head Occupational Therapist
Occupational Therapy Mental Health Managers Forum

Mrs Arlene Healey
Centre Manager/Consultant Family Therapist

Mrs Billie Hughes
Clinical Services Manager

Mr Billy McCullough
Senior Lecturer (retired)

Mrs Maureen Ferris
Assistant Director of Nursing

Dr Carolyn Mason
Nursing and Midwifery Advisory Group

Dr Janet MacPherson
Consultant Psychiatrist

Ms Linda Hutchinson
Carer Advocate,
C.A.U.S.E. for Mental Health.

Ms. Cathy McCullough
Young Persons representative

Mrs Joelle Gartner
Teacher, Psychotherapist

Ms. Kimberley McConkey
Young Persons representative

Mr Seamus McGarvey
Sperrin Lakeland Trust

Dr Lisheen Cassidy
Consultant Child & Adolescent Psychiatrist

Dr Harry Rafferty
Educational Psychologist

Dr Aisling McElearney
Education Advisor, NSPCC

Dr John Hunter
Inspector
ETI

Ms Bronagh Muldoon
NSPCC

Dr Maura McDermott
Consultant Child and Adolescent Psychiatrist

Mr Sean Ferrin
Secretary to the Committee

Psychological Wellbeing Sub-Group

Mr Stephen Dornan
Children Services Manager

Dr Tom Teggart
Consultant Clinical Pscyhologist

Mrs Arlene Healey
Centre Manager/Consultant Family Therapist

Mr Billy McCullough
Senior Lecturer (retired)

Mrs Marie Roulston
Children's Services

Mr Hugh Griffiths
Senior Lecturer in Social Work

Tier 1 & 2 Sub Group

Ms Moira Davren
Convenor – Child and Adolescent MH working Committee

Dr Noel McCune
Consultant Child and Adolescent Psychiatrist

Ms Bronagh Muldoon
Children's Services Manager

Mrs Maureen Ferris
Assistant Director of Nursing

Dr Carolyn Mason
Nursing and Midwifery Advisory Group

Mr David Gilliland
Childcare Directorate

Dr Janet Bothwell
Consultant Community Paediatrician

Dr Aisling McElearney
Education Advisor, NSPCC

Ms Ita Toner
Health Visitor

Tier 3 & 4 Sub Group

Mrs Billie Hughes
Clinical Services Manager

Dr Maura McDermott
Consultant Child and Adolescent Psychiatrist

Ms Jackie Nelson
Senior Clinical Nurse Specialist/
Clinical Nurse Manager, CAMHS

Ms Brenda Byrne
Head OccupationalTherapist
Occupational Therapy Mental Health Managers Forum

Ms Linda Hutchinson
Carer Advocate,
C.A.U.S.E. for Mental Health.

Dr Karen Kearney
Consultant Clinical Psychologist

Dr Lisheen Cassidy
Consultant Child & Adolescent Psychiatrist

ANNEXE 5

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ANNEXE 6

GLOSSARY

(ADHD) Attention Deficit Hyperactivity Disorder

(A&E) Accident and Emergency

(AHP) Allied Health Professionals

(AHR) Acute Hospitals Review

(ASD) Autistic Spectrum Disorder

(CAMH) Child Adolescent Mental Health

(DHSSPS) Department of Health, Social Services and Public Safety

(EOTAS) Education other than at School

(EU) European Union

(HAS) Health Advisory Service

(H&PSS) Health and Personal Social Services

(IQ) Intelligence Quotient

(KSF) Knowledge for skills framework

(LAC) Looked After Children

(NI) Northern Ireland

(NICAPS) National Inpatient Child and Adolescent Psychiatry Study

(NICE) National Institute Clinical Excellence

(NIO) Northern Ireland Office

(NSF) National Service Framework

(PCIS) Patient Centred Information System

(PMH) Primary Mental Health

(RCSLT)	Royal College of Speech and Language Therapists
(R&D)	Research & Development
(SEHD)	Scottish Executive Health Department
(SHSSA)	Strategic Health and Social Services Authority
(SLCN)	Speech, Language and Communication Needs
(SLT)	Speech and Language Therapy
(UK)	United Kingdom
(WTEs)	Whole Time Equivalents

THE BAMFORD REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY
(NORTHERN IRELAND)

FORENSIC SERVICES

October 2006

THE BAMFORD REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY (NORTHERN IRELAND)

FORENSIC SERVICES

CONTENTS

FOREWORD

The Bamford Review of Mental Health and Learning Disability consists of a number of interlinked reviews under one overarching title and encompasses policy, services and legislation.

The Review Steering Committee presides over the work of 10 major Expert Working Committees, 4 of which commenced their work by April 2003 and the remaining 6 by November 2003.

In consultation with Government we have agreed to produce our reports separately in a phased manner.

This report represents the first major review of Forensic Mental Health and Learning Disability Services in Northern Ireland. Although there have been some welcome improvements in services in recent years, current services in Northern Ireland fall very substantially below those available in other parts of the United Kingdom. In producing this report Fred Browne and his committee have integrated evidence and experience from a very broad range of stakeholders. I am grateful for all their hard work.

All of our committees have adopted an evidence-based approach, drawing on existing relevant information and research and, where necessary, commissioning research. Exemplars of best practice from local, national and international sources are informing our reports.

We have maintained a clear vision for Mental Health and Learning Disability services in Northern Ireland. Widespread consultation with stakeholders has endorsed our vision and the strategic direction of the Review. A feature of the Review process is the contribution of service users and carers across both Mental Health and Learning Disability; their insights, advice and guidance continue to be invaluable.

As Chairman of the Review I wish to thank all who have contributed to the preparation of this report.

Roy McClelland (Professor)
Chairman

October 2006

Executive Summary

This report makes detailed recommendations on the development of Forensic Mental Health and Learning Disability Services in Northern Ireland. The report is interlinked with the other reports of the Bamford Review of Mental Health and Learning Disability (Northern Ireland). It shares the values and principles that are common to the whole Review and it takes account of the needs of all the interested parties, including forensic service users and their carers, service commissioners, providers and the wider public. At its heart the report is concerned with the development of services for mentally disordered offenders and others with similar needs. Most of the recommendations stem from 2 underlying themes:

1. **People who are subject to the Criminal Justice System (such as prisoners, people who are on probation, on bail or attending court or police stations) have high levels of mental disorder. Currently the services to meet the needs of these people are inadequate. These members of our society should not be deprived of assessment, treatment or care for their mental disorders because they are subject to the Criminal Justice System. Rather they should have access to services that are equivalent to those available to the rest of our society. Where people are subject to the Criminal Justice System, services should be provided in co-operation with the Criminal Justice Agencies.**

2. **The majority of people in our society who suffer from mental disorder pose no increased risk of causing harm to others. However, some people suffer from mental disorder that is associated with significant risks of causing serious harm to others. It is in the interests of these individuals and the wider society that they are provided with evidence-based treatment and care that helps minimise the risks. The Health and Personal Services (HPSS) should provide services to identify and assess people suffering from such disorders, whether they are currently in hospital, in prison, in police stations or in the community and the HPSS should provide these individuals with appropriate treatment, care and safeguards. Where such individuals are subject to the Criminal Justice System a joint co-operative approach is required between the HPSS and the Criminal Justice Agencies.**

This report examines these and related issues in detail and makes a series of recommendations. Implementation of these recommendations will lead to important changes in peoples' lives, including the following:

- People who suffer from mental disorder and who are subject to the Criminal Justice System or whose disorder poses significant risks of serious harm to others will have their needs identified more effectively and they will be provided with timely access to assessment, support, treatment and care, for example:
    - Prisoners suffering from major mental illness will no longer have to wait in prison for lengthy periods of up to several years before they can be transferred to hospital to receive the treatment they require;
    - It will become possible for unsentenced prisoners and other individuals to be admitted to a high security hospital facility for detailed assessment so that properly informed decisions can be made about further placement, treatment and care;

  - Service users will receive appropriate psychotherapeutic treatments;
  - Mentally disordered people in police stations will have access to a range of mental health and learning disability services;
  - People who have so far not received adequate services, such as those sufering from personality disorder and other developmental disorders, will have access to assessment and evidence-based treatments;
  - People will no longer receive treatment in conditions of security and restriction which is greater than their condition and circumstances require.

- Service users will find that services are of high quality and that service providers work effectively together to assess and meet their needs, for example:
  - Services will be based on agreed values, principles and purposes and will be developed through joint planning between the relevant parties, including service users and carers;
  - Services will be evidence-based and developed to meet assessed needs;
  - Services will establish appropriate arrangements for information sharing, joint working, continuing improvement and mental health promotion.
- Carers will experience services that are developed and delivered to take account of their needs, for example carers of mentally disordered prisoners will receive appropriate information and support.
- The public will be better informed about mental disorder and the relationships between mental disorder and risk. They will be assured that services work together effectively to identify and minimise the risks associated with mental disorder and also that services are efficient and provide value for money.
- Staff will be recruited in accordance with workforce plans that meet the needs of services. Staff will be appropriately trained and supported.

In order to achieve these outcomes the Review makes the following recommendations:

A Regional Forensic Network

A Regional Forensic Network should be established to co-ordinate the planning and delivery of forensic services at regional and local levels.

Police Stations

The Review Implementation Team should lead the co-ordination of planning and developing mental health and learning disability services to police stations in liaison with the Regional Forensic Network.

Courts

Service commissioners should commission a full range of statutory and independent mental health and learning disability services to meet the needs of mentally disordered people attending courts.

In Year 5, when forensic mental health and learning disability services in Northern Ireland have increased in size and capacity according to the schedule proposed in Chapter 12, a detailed option appraisal should be undertaken to consider the provision of assessments and other services for the courts by alternative means, including by service level agreements.

Prisons

The project overseeing the transfer of lead responsibility for prison healthcare to the NHS must ensure that joint working arrangements with all relevant mental health and learning disability service providers are agreed and published beforeApril 2007. It must be demonstrated that service providers have sufficient resources and capacity to meet the identified needs.

The Review supports the recommendations made by Professor McClelland and colleagues (2005)[13] in relation to the assessment, treatment and care of prisoners on committal to prison.

A multi-agency consortium should be formed to promote the development of psychotherapeutic expertise in the assessment and management of behavioural disturbance, personality disorder and offending behaviour. The lead should be taken by Department of Health, Social Services and Public Safety (DHSSPS) with input from criminal justice agencies and the relevant health sector bodies.

Probation

Probation Board for Northern Ireland (PBNI), the Regional Forensic Network and the Implementation Team should agree joint arrangements to assess and monitor the needs and should provide services for individuals, their carers, their representatives, service providers and the wider community.

Secure Inpatient Services

The current arrangements for high secure services for people in Northern Ireland have unacceptable gaps in service provision. The Department of Health, Social Services and Public Safety (DHSSPS) must take the lead in urgently finding solutions to the current obstacles to treatment and care in conditions of high security.

The Review recommends the provision of an additional secure facility in Northern Ireland to meet the identified high and medium secure needs of service users. The regional high and medium secure facilities should be complemented by local low secure facilities and community facilities to form a range of short, medium and longer stay facilities that meet the needs of forensic service users. In particular the DHSSPS must plan and develop long stay medium secure services and step-down low secure and community services.

Community Forensic Services

The 5 Community Forensic Teams that are currently partly staffed and funded require the necessary funding and workforce planning from the DHSSPS to ensure they are developed to full operational capacity and supported by appropriate facilities in the community. Community forensic services should be further developed to meet assessed need.

Forensic Learning Disability Services

Co-ordinated services must be planned and developed to meet the short, medium and longer term needs of service users at high, medium and low levels of security and in the communityA regional inpatient and community forensic learning disability service should be developed immediately which supports the further development of 5 localised and regionally co-ordinated teams.

The DHSSPS must urgently address the current obstacles to service users with learning disability receiving inpatient care, including the lack of step-down services at low security and in the community.

Risk Assessment and Management

The DHSSPS, Northern Ireland Office and relevant others should produce a comprehensive interagency and community response to help offenders reduce their risks of offending and to provide protection to the public from high risk sexual and violent offenders, irrespective of whether or not they suffer from mental disorder.

Personality Disorder

The DHSSPS should ensure that assessment and treatment services are made available to offenders suffering from personality disorder along with support for their carers. Services should be provided in prisons and in the community. Services in the community should comprise outpatient, day patient and therapeutic community services. In the prisons outpatient and day patient services should be provided. A residential secure service should also be developed. Services should be evidence-based or, where there is inadequate evidence, they should be established in a way which gathers and contributes to the evidence.

Offending by Adults with Asperger’s Syndrome or High Functioning Autism (AS/HFA)

The Regional Forensic Network should co-ordinate a programme of training for staff in the identification, assessment, treatment and care of people suffering from AS/HFA.

Services for Women

Service commissioners and providers must ensure that services are gender sensitive. The DHSSPS should consider whether a separate low secure facility is more appropriate to the needs of women service users than the current provision in Shannon Clinic. Community services should be provided individually to male and female users on the basis of individual needs and must be gender sensitive.

Forensic Psychotherapy

The DHSSPS, the Regional Forensic Network, service commissioners and providers must ensure that planning and development of all inpatient and community mental health and learning disability forensic services incorporate and integrate a range of multi-disciplinary psychotherapeutic approaches. All clinical staff working in forensic services must be provided with the appropriate opportunities and support to develop high levels of psychotherapeutic knowledge and skill. The planning and delivery of forensic services must also include the provision of services by specialist Psychotherapists and Forensic Psychotherapists.

Regional Guidance and Procedures

The DHSSPS should establish reviews including:

- assessment of fitness for interview, fitness to attend court and related matters;
- the appropriate adult scheme; and
- the Discharge Guidance.

Quality Assurance

Standards and mechanisms for assuring the quality of mental health and learning disability services must be developed by the relevant regional body with responsibility for quality assurance, service commissioners, providers and by the Regional Forensic Network.

Mental Health Promotion

Service commissioners, providers, the Regional Forensic Network and the regional body with responsibility for mental health promotion should identify opportunities for mental health promotion within the Criminal Justice System and forensic mental health and learning disability services and ensure that appropriate services are provided and their impact evaluated.

The DHSSPS should lead the establishment of a Regional Prison Mental Health Promotion Group to address mental health promotion and suicide prevention.

Research and Assessment of Need

Research should be commissioned to assess and monitor the needs for forensic services of people in the Criminal Justice System, in inpatient settings and in the community . The DHSSPS must commission an assessment of needs to determine the numbers of people from Northern Ireland who require treatment in conditions of high, medium and low security and in community facilities. The assessment should include people suffering from mental illness, severe mental impairment and from personality disorder and other developmental disorders. It should encompass those who are currently receiving services and those who are currently unable for legal or other reasons to avail of such assessment, treatment and care.

The joint DHSSPS/Northern Ireland Prison Service (NIPS) project to transfer responsibility for prison healthcare to the National Health Service (NHS) must ensure that a detailed assessment of the needs of mentally NHS disordered prisoners and their carers is carried out. An assessment should also be commissioned to examine the needs of service users who are placed in prison healthcare centres and the options for alternative services and placements.

The NIPS should commission research on the feasibility of reducing the number of mentally disordered people in prison by providing a broader range of facilities in the community, including lower security placements for mentally disordered women.

Research should also be commissioned to evaluate the methodology of assessing people in police stations and prisons with a view to ensuring the accurate identification of specified forms of mental disorder and need.

Information Systems

The DHSSPS should ensure that development of Information Systems within the HPSS takes full account of the need to provide health and social care for people subject to the Criminal Justice System. Where appropriate, health and social services systems should link with Criminal Justice Systems in support of joint working.

Learning and Development

The DHSSPS in partnership with Criminal Justice Agencies should ensure that an assessment is undertaken of the learning and development needs of stakeholders in the Criminal Justice System and in health and social services.

Training strategies should be devised and implemented to meet the identified needs for both induction training and for continuing professional development, closely integrating training with clinical practice.

Recruitment and Retention

The DHSSPS must ensure that development and maintenance of forensic services is supported by robust workforce planning.

Funding

Current services are under-developed. Funding is required for the development of mental health and learning disability inpatient services at high security, long stay medium security and low security. There are also needs to provide accommodation and day facilities in the community, mental health and learning disability community teams, services for mental health and learning disability services to the prisons, and to support people in police stations, in courts and in contact with probation. Funding is also required to develop comprehensive personality disorder services and psychotherapy services.

Conclusion

The Review believes that all of these recommendations and the others detailed in this report are necessary and realistic and that the objectives are achievable over the next 15 years through a planned and co-ordinated approach that involves all the relevant parties working together to meet the needs. An implementation plan is included to assist with the sequencing and prioritisation of the recommendations.

Finally it must be acknowledged that the development and provision of services for mentally disordered offenders and others with similar needs is a highly emotive topic. Perhaps the greatest challenge that we all face is to recognise our capacity for prejudice, discrimination and rejection of these disadvantaged individuals, to acknowledge their legitimate needs and to make the necessary and sustained commitments to action, as described in this report.

CHAPTER 1

THE NEEDS OF SERVICE USERS, CARERS AND SERVICE PROVIDERS

1.1 People in need of forensic services are some of the most marginalised, stigmatised, vulnerable and poorly understood individuals in Northern Ireland and the services to meet their needs are some of the least developed. This report reviews mental health and learning disability services for mentally disordered offenders and others with similar needs in Northern Ireland. The report makes recommendations for action in relation to specialist Forensic Services and also the range of other mental health and learning disability services. This report should be read in conjunction with the other reports from this Review. McCall[1] has also completed a literature review and needs assessment of forensic services in Northern Ireland.

1.2 While forensic service users have features in common, each person must be respected as a unique individual. Many have experienced multiple disadvantages during childhood such as frequent family separations, physical, psychological and emotional abuse and neglect, lack of close, confiding and supportive relationships, inconsistent parenting and alienation from school and community. As a consequence, many have personality difficulties such as chronic low self esteem, lack of empathy for others, difficulties in relationships with authority and poor impulse control. Many have resorted to abuse of alcohol and other substances which appear to offer temporary relief from mental distress, but which contribute further to disturbance of mood and behaviour and to social alienation. Abuse of substances may precipitate the onset of mental illness or aggravate established illness. Those who develop mental illness may be further distressed by severe disturbances of thought, perception and mood. Major illnesses often impair the capacity to appreciate the illness and the need for treatment. Offending behaviour may occur as a consequence of a chaotic and disintegrated phase in the life of the individual. The combination of some or all of these elements often leads to offending behaviour and societal reactions that include fear, rejection and discrimination.

1.3 The needs of forensic service users are not just narrowly confined to the amelioration of symptoms of mental disorder. Services responding to therapeutic and care needs must address the wide range of problems specific to each individual with the aim of helping him or her integrate into society. Where the individual has behaved in a violent or dangerous manner this must include careful assessment of risk.

1.4 The needs of carers must also be addressed. Carers may have experienced difficulties understanding the nature of the service user's problems and providing appropriate support. They may have been traumatised or become alienated. Carers of forensic service users require assessment of their own needs and provision of the necessary information and support.

1.5 Staff who work with forensic service users and carers must have the understanding and ability to deal with the wide range of problems that present. They must possess the abilities to work in partnership with users, carers and many others and to view situations from many different perspectives. Work of this nature generally evokes a wide range of emotions and staff require training and support to help them respond appropriately. Staff providing forensic services encounter 2 systems, the Criminal Justice System and the Health and Social Services. These 2 systems have different purposes and cultures and it is inevitable that tensions will arise. Staff working across these interfaces must be sensitive to the ethical and practical problems that can arise for service users and carers and must be able to help negotiate solutions. Staff must be alert to the restrictions and controls that may be placed on service users that create an imbalance in power between staff and service users and may render service users liable, often in subtle ways, to infringement of their rights. Service users may be subject to discrimination from other service providers such as over-emphasising of risks to others related to mental disorder or by reluctance to offer appropriate community services.

1.6 Because of their multiple disadvantages service users often have difficulty identifying and articulating their needs. At present advocacy services are at early stages of development. Forensic service users and their carers do not at present come together as groups to voice their needs for improved services. These factors in turn make service users and their carers particularly vulnerable to receiving inadequate care. Stigma and discrimination may influence Government and commissioners of services, for example by failing to take adequate account of the needs of forensic service users and by failing to safeguard proper provision for them.

1.7 The challenges for the decision makers and for the rest of society are to recognise and respect service users and carers as fellow members of our society, to ensure that they receive appropriate therapeutic interventions and care which facilitate their journey towards productive and satisfying lives and their integration within society.

CHAPTER 2

INFORMATION, VALUES, PRINCIPLES AND STANDARDS

INTRODUCTION

2.1 It is essential that during the planning and delivery of Forensic Services full account is taken of the available information and evidence. Values and principles are also essential in directing our goals. A vision for services that combines an evidence-based approach and a values-based approach is essential[2]. There must be arrangements to take information from and contribute to the "evidence cycle" that gathers and evaluates the available evidence, identifies gaps in information, prioritises and implements research and generates and disseminates evidence. There must also be explicit statements of the values and principles upon which the development and delivery of future services should be founded. Both must be integrated into the planning of services and their delivery.

EVIDENCE

2.2 The need for local research and development has been identified in the Report by the Adult Mental Health Working Committee[83] (chapter 7.21) which has proposed a Northern Ireland Research and Development Strategy. That strategy must encompass forensic services. Priorities for Research and Development in Forensic Services are identified in subsequent chapters in this report.

VALUES AND PRINCIPLES

2.3 The vision of this Review is:

- valuing those of us with mental health needs, including rights to full citizenship, equality of opportunity and self-determination;
- addressing the challenges facing people with mental health needs; and
- a process of reform, renewal and modernisation of services that will make a real and meaningful difference to the lives of people with mental health problems, and to their carers and families.

2.4 The values of the Review state that people with mental health needs and their carers should receive services which:

- offer proper treatment and care to facilitate their journey towards productive and satisfying lives and their integration into our society;
- respect them as individuals – through openness in the providing of information, respect and courtesy in individual interactions with service users, true partnership and empowerment in service planning and provision – with Government, providers and the wider society each accepting their respective responsibilities; and

- demonstrate justice and fairness – resources for services should be allocated and managed according to criteria which are transparent, and which demonstrate equity

2.5 The principles for the Review's Strategic Framework are:

- partnership with users and carers in the development, evaluation and monitoring of services;
- partnership with users in the individual assessment process and all therapeutic interventions of care and support;
- delivery of high quality, effective therapeutic interventions, care and support;
- equity of access and provision of services, including the needs of people from minority cultures, people with disabilities, people subject to the Criminal Justice System;
- provision of services which are readily accessible;
- delivery of continuity of care and support for as long as is needed;
- provision of a comprehensive and co-ordinated range of services and accommodation based on individual needs;
- taking account of the needs and views of carers, where appropriate, in relation to assessment, therapeutic interventions, care and support;
- provision of comprehensive and equitable professional and peer advocacy , where required or requested;
- promotion of independence, self-esteem, social interaction and social inclusion through choice of services, facilitation of self management, opportunities for employment and social activities;
- promotion of safety for service users, carers, providers and members of the public;
- provision to staff of the necessary education, training and support; and
- services subject to quality control, informed by the evidence.

PRINCIPLES FOR FORENSIC SERVICES

2.6 The principle that people who are subject to the Criminal Justice System should have equity of access and provision of services adopted elsewhere has been referred to as the "Principle of Equivalence"[3]. It is of fundamental importance to service users, carers and service commissioners and providers. People who are in police stations, on bail, attending court, in prison, on probation or otherwise subject to the Criminal Justice System must have equity of access and provision of the full range of statutory mental health and learning disability services. This principle creates a substantial agenda for change.

2.7 The Review recommends that 4 additional principles should be adopted in relation to forensic services:

1. there should be joint co-operative planning between the Criminal Justice Agencies and the Health and Personal Social Services (HPSS) and joint delivery of services in order to best meet the needs of service users and carers.

Mentally disordered offenders and others with similar needs should receive treatment, care and support for their mental disorder that is:

2. as far as possible in the community, rather than in inpatient settings;

3. under conditions of security and restriction no greater than as is justified by the degree of danger they present to themselves or others; and

4. open, accountable and subject to external review.

STANDARDS FOR THE DEVELOPMENT AND DELIVERY OF FORENSIC SERVICES

2.8 The Review has developed the following 10 interconnected Standards that it believes should be applied to guide the planning and delivery of Forensic Mental Health and Learning Disability Services in Northern Ireland:

Standard 1. A Co-Ordinated Joint Strategic Approach

2.9 The development and delivery of comprehensive Forensic Mental Health and Learning Disability Services require contributions from many sources including service users and carers, commissioners and providers of services, representatives from forensic mental health and learning disability services, from Criminal Justice Agencies in the statutory, voluntary and community sectors and from the wider community. A shared approach must be adopted that respects the contributions of each organisation and each individual and co-ordinates service development and delivery at regional and local levels.

Standard 2. Evidence, Principles and Purposes

2.10 Forensic services should take account of the available evidence on efficacy of service models and interventions and contribute to the generation of further evidence. They should operate in accordance with explicit values and principles and have clear purposes. Forensic services should be developed and delivered in response to need. There must be robust mechanisms to assess and meet the needs of each individual, his or her carers and representatives, service providers and the wider community. There must also be mechanisms to assess the impact of service developments on need.

Standard 3. Organisational Structures and Interconnections

2.11 Forensic services comprise a range of components, such as services to people in prison, community forensic services and secure inpatient services. All components must have clear organisational structures, accountability and governance arrangements. Each component must be co-ordinated at regional and local levels to work together with all other interconnecting services in an efficient and effective manner. Forensic services should work flexibly in partnership and in support of interconnecting health and social services providers and with Criminal Justice Agencies in the statutory, voluntary and community sectors.

Standard 4. Comprehensive and Accessible Services

2.12 Forensic services should be comprehensive to include the provision of timely, accessible and high quality assessment of needs, treatment and care for service users and support for their carers with continuity of services for as long as required. Services should assess the full range of needs (physical, psychological and social) and should provide services to meet those needs in accordance with best practice. Forensic Services should be developed and delivered in a manner that promotes openness and good communication between all relevant people, while respecting the rights of the individual for privacy and confidentiality. Information sharing protocols and joint working protocols should be developed between the Criminal Justice System and mental health and learning disability services.

Standard 5. Risk Assessment and Management

2.13 Forensic services should assess and manage the risks for which they have responsibility. They should make all reasonable efforts to reduce the relevant risks with the resources at their disposal but there must also be widespread recognition that risk is inherent in the work of forensic services and cannot be eliminated. The work of forensic services should be supported by the development of interagency and multi-disciplinary risk assessment and management protocols and procedures.

Standard 6. Quality Assurance

2.14 Forensic services must have robust and demonstrable quality assurance mechanisms that include setting standards and assessing the performance and quality of services. These should include internal mechanisms such as audit and also external review.

Standard 7. Mental Health Promotion and Education

2.15 Promotion of mental health is essential to prevention and reduction of need. Forensic services must help develop understanding of the routes whereby an individual may become a mentally disordered offender and the interventions that could be made to produce more favourable outcomes. Forensic services should liaise closely with the regional body responsible for mental health promotion[84]. In addition, forensic services should contribute to public education to promote understanding and help prevent stigmatisation and discrimination.

Standard 8. Information, Research and Innovation

2.16 Forensic services should have information strategies that include contributing to evidence-gathering and research. Services should promote enquiry and innovation. Information Technology should be used where appropriate to enhance service quality and efficiency.

Standard 9. Recruitment, Retention and Developing a Skilled Workforce

2.17 The development and maintenance of forensic services must be supported by a workforce planning strategy that ensures the recruitment and retention of staff who are equipped with the appropriate personal qualities and professional qualifications. There must be a Learning and Development strategy to provide staff with the necessary knowledge, skills and support throughout forensic services and the interconnecting health and social services and in Criminal Justice Agencies. Service users and carers have learning and development needs that should be addressed.

Standard 10. Sustainable and Transparent Funding

2.18 The development and maintenance of forensic services requires appropriate funding from the relevant sources. Funding should be delivered in accordance with long term plans that ensure sustainable development of services. Funding arrangements must support the joint co-ordinated planning and delivery of services. There must be mechanisms that demonstrate that monies made available to services have reached their intended targets.

ORGANISATIONAL STRUCTURES TO SUPPORT THE CO-ORDINATED PLANNING AND DELIVERY OF FORENSIC SERVICES

2.19 This Report makes recommendations for the development and delivery of forensic services in Northern Ireland over the next 15 years. Services must be provided to meet the needs of all service users and demonstrate efficient use of resources. Those who are charged with the duty of planning, implementing and delivering forensic services bear a heavy burden of responsibility to all the stakeholders including service users and carers, the wider public and staff in the Health and Social Services and in the Criminal Justice System.

2.20 The purpose of this Review is to provide a vision for the development of forensic and other mental health and learning disability services in Northern Ireland. It is essential that arrangements are established to revise and update plans in response to changing circumstances, while maintaining an overall strategic direction. The Review believes that strategic planning of services must be an ongoing process with the continuing development of strategic plans for short, medium and long time frames.

2.21 A Forensic Regional Advisory Group was established in 2005 to co-ordinate the development of forensic services in Northern Ireland. The Review welcomes this development. Chapter 12 gives further details of the Review's recommendations on implementing the necessary changes to support the planning and development of forensic services. These include regional and local co-ordination through the formation of a Regional Forensic Network.

Recommendations

1. A Regional Forensic Network should co-ordinate and lead the strategic planning of forensic services in Northern Ireland.

2. Strategic planning must be guided by evidence and by values and principles. The Regional Forensic Network must establish systems of gathering the necessary information and evidence to inform the further development of services.

3. The Regional Forensic Network should establish explicit values and principles to guide the planning and development of forensic services. The values and principles adopted by this Review (see 2.3 - 2.5) are recommended. In addition the following principles are recommended for forensic services:

   i. there should be joint co-operative planning between the Criminal Justice Agencies and the Health and Personal Social Services and joint delivery of services in order to best meet the needs of service users and carers;

   Mentally disordered offenders and others with similar needs should receive treatment, care and support for their mental disorder that is:

   ii. as far as possible in the community, rather than in inpatient settings;

   iii. under conditions of security and restriction no greater than as is justified by the degree of danger they present to themselves or others; and

   iv. open, accountable and subject to external review.

4. The planning and development of forensic services should take full account of the 10 Standards identified in this Report.

CHAPTER 3

POLICE STATIONS

INTRODUCTION

3.1 The police service is a major agency in contact with mentally disordered people in the community. It acts as an important 'gatekeeper' to the mental health and learning disability services, especially in relation to situations that arise in public places.

3.2 In police stations there are two main ethical reasons to ensure that individuals who are suffering from mental disorder are identified:

- the individual may be suffering from a mental disorder that interferes with his or her capacity to protect his or her rights and best interests while in the police station; and
- the individual may require treatment for his or her condition.

3.3 Thus services are required at police stations to:

- identify and assess the needs of people who are suspected or confirmed as suffering from mental disorder;
- offer appropriate support, treatment and care to service users;
- provide appropriate information and support to carers; and
- advise the Criminal Justice System, where appropriate, on the implications of the service user's condition.

CURRENT SERVICES

3.4 Police stations are provided with medical services by Forensic Medical Officers (FMOs) most of whom are general practitioners and who conduct most of the assessments of individuals suspected of suffering from mental disorder. In 1998 a police liaison scheme for Mentally Disordered Offenders (the "MDO Scheme") was established in Musgrave Street Police Station in Belfast. Two community mental health nurses are employed to screen custody records, carry out mental health assessments on selected individuals, provide health promotion and liaise with the appropriate agencies to arrange treatment and support. They also provide advice to FMOs, courts, legal representatives and others. In addition the nurses provide training to police to help them understand the nature of mental disorders and the problems experienced by those suffering from mental disorder. This MDO Scheme has remained in place and is expected to become part of the Eastern Health and Social Services Board Community Forensic Service. It remains confined to the Belfast area.

3.5 Key findings from the MDO Scheme[4] were:

- 16% of custody records met one or more assessment criteria for mental disorder;
- 91% of those who underwent assessment were judged to have a mental health problem;
- typically these were single unemployed males in their early 30s and living alone;
- two thirds had a history of having been in one or more health, social services or criminal justice institutions, 47% had received inpatient care; and
- almost half had been in prison.

3.6 The most commonly recorded diagnoses were:

- depression (44%);
- substance misuse (15%);
- schizophrenia/paranoid psychosis (11%); and
- anxiety (11%).

3.7 No information is available in relation to mentally disordered offenders presenting to police stations in other parts of Northern Ireland.

3.8 Users and carers made positive comments in relation to the MDO Scheme. Comments also included lack of understanding of mental health problems and the stigma associated with police escort. Other key issues highlighted in consultation with stakeholders were:

- the MDO Scheme was generally regarded as beneficial;
- the scheme was considered to be under-resourced;
- there were communication problems between organisations and difficulties sharing information;
- there was uncertainty in defining fitness for interview and the roles of appropriate adults;
- there were difficulties in managing people viewed as suffering from personality disorder; and
- there were difficulties admitting to hospital people who were suffering from temporary disorders.

3.9 The literature review by McCall[1] provides details of the characteristics of people detained in police stations and those placed in hospital as a place of safety the use of the appropriate adult scheme, the needs of carers, police liaison schemes and the use of educational interventions for police officers. There is evidence to indicate that police liaison schemes and education of police officers are effective interventions.

STANDARDS

Application of Standards

3.10 The 10 standards identified in Chapter 2 have been applied to the consideration of planning and delivery of services in police stations.

Standard 1. A Co-Ordinated Joint Strategic Approach

3.11 There must be effective co-ordination between Criminal Justice and Health and Social Services Organisations and equity of access and provision of services for people subject to the Criminal Justice System. Mental health and learning disability services such as Community Mental Health Teams, Crisis Resolution Services, Community Forensic Teams, Learning Disability and Alcohol and Substance Misuse Services are being developed across Northern Ireland. It is essential that these developing services are co-ordinated at local and regional levels to provide a full range of mental health and learning disability services for mentally disordered people in police stations.

Recommendations

5. Service commissioners must commission a full range of statutory mental health and learning disability services to meet the needs of mentally disordered people detained in police stations.

6. Providers of statutory, voluntary and community mental health and learning disability services must ensure they provide equity of access and provision of services for people detained in police stations.

7. Mental health and learning disability services to people detained in police stations should be provided locally and co-ordinated regionally. The Department of Health, Social Services and Public Safety (DHSSPS) should lead this co-ordination in liaison with the Regional Forensic Network.

Standard 2. Evidence, Principles and Purposes

3.13 The planning of services requires good quality evidence and explicit principles and purposes. Although valuable information has been obtained from the MDO Scheme there remain substantial gaps in our knowledge of the needs of mentally disordered people and their carers in police stations throughout Northern Ireland.

3.14 The principles of this Review include the provision of advocacy services. At present there are various people who may adopt an advocacy role for service users in police stations, including lawyers, appropriate adults, health, social services staff, probation staff and members of voluntary organisations. However, there is no-one specifically charged with the responsibility for acting as an advocate for mentally disordered service users within police stations. It is recommended that the advocacy services attached to community mental health and learning disability services should be extended to include police stations.

Recommendations

8. Research should be commissioned to assess the needs of mentally disordered people and their carers in police stations throughout Northern Ireland. This research should include recommendations leading to the establishment of systems to monitor ongoing need and the impact of services on need.

9. Advocacy services associated with community mental health and learning disability services should be extended to include police stations.

Standard 3. Organisational Structures and Interconnections

3.15 Mental health and learning disability services to police stations must have clear organisational structures, accountability and governance arrangements. Each component must be co-ordinated at regional and local levels to work together with all other interconnecting services in an efficient and effective manner. Statutory mental health services should work in partnership with voluntary and community sector providers. It is likely that different patterns of service delivery will be required to meet the different needs in individual police stations throughout Northern Ireland, for example, the model that has been developed for a large city centre police station in Belfast may not be appropriate for a smaller rural station.

Recommendation

10. Clear organisational structures, accountability and governance arrangements must be agreed for mental health and learning disability services to police stations.

Standard 4. Comprehensive and Accessible Services

Assessment of Health Needs

3.16 It can be a difficult task for the FMO to assess an individual in a police station. For example there may be very little background information available and the individual may be intoxicated, unco-operative, violent or emotionally disturbed by the circumstances that have brought him or her to the police station. Not all people are registered with a general practitioner, but for those who have current health records it would be helpful if these were accessible to the FMO. Ultimately it is expected that information technology systems will be developed throughout the National Health Service (NHS) that can provide appropriate access to staff providing assessment and healthcare in police stations, however, these systems may take a number of years to develop. In the interim it is essential to review and improve the existing systems.

Recommendation

11. Service providers should develop information systems that enable FM0s and staff working in mental health and learning disability services to gain appropriate access to the health records of people detained in police stations.

3.17 The current accuracy of the systems in police stations for identifying mental disorder and mental health needs is unknown. The arrangements depend upon police, lawyers, users, carers and others raising the suspicion of mental disorder and then the FMO, perhaps with the assistance of mental health staff, correctly identifying the mental disorder or need. At present there is very little scientific evidence to inform practitioners on the most efficient and effective methods of assessing suspects in police stations for the presence of mental disorder. Screening procedures should be directed towards explicit objectives such as identifying mental disorders that may place the individual at risk of causing harm to themselves or others or being unable to protect their best interests. Screening tools must be evidence-based for the environment of a police station. Research should be commissioned to establish an appropriate evidence base.

Recommendation

12. Research should be commissioned to evaluate the methodology of assessing suspects in police stations with a view to ensuring the accurate identification of specified forms of mental disorder and need.

Fitness for Interview

3.18 FMOs are frequently asked to determine whether an individual is fit to be interviewed.The Code of Practice for the Police and Criminal Evidence (Northern Ireland) Order 1989[5] acknowledges that a person may be unfit to be questioned on account of being under the influence of drink or drugs, but it does not address the needs of people who may be unfit for interview on account of mental disorder.

3.19 The Association of Forensic Medical Officers of Northern Ireland and the Association of Forensic Physicians in England, Scotland and Wales have agreed to work on the basis that, for a person to be fit to be interviewed he or she must:

- able to understand the questions that are being put to them;
- understand why particular questions are being put to them, and to understand the nuances behind the questions; and
- be able to give a good account of themselves in their answer.

3.20 FMOs and Forensic Physicians have defined unfitness for interview as follows:

'A detained person may be unfit for interview when conducting an interview could worsen any existing physical or mental illness to a significant degree, and/or anything said or done by the detained person at the time of interview may be considered unreliable in subsequent court proceedings, because of the physical or mental state of the detainee.'

3.21 There is a need for clear and approved guidance on this issue of fitness for interview and related issues such as:

- the appropriate disposal(s) for an individual found unfit to be interviewed;
- whether a person may be deemed permanently unfit for interview; and
- whether a person who is being charged without interview may be unfit to be charged.

Recommendation

13. The DHSSPS in partnership with Criminal Justice Agencies should establish a group comprising relevant stakeholders to produce guidance on assessment of fitness for interview and related matters.

The Appropriate Adult Scheme

3.22 When a police officer has any suspicion that a person due to be interviewed as witness, victim or suspect may be mentally disordered, he must contact an appropriate adult[6]. The appropriate adult scheme provides certain safeguards for mentally disordered people in police stations. However, a number of concerns have been raised about the scheme. These include:

- the criteria for suspected mental disorder are potentially very broad and do not appear to be adequately targeted at those who are most vulnerable;
- research[7] has indicated that in practice there is a failure by police to identify mental disorder and this implies that the interests of mentally disordered people have not been demonstrably safeguarded;
- there are difficulties in finding people to act as appropriate adults. Social workers may perform this function, but Trusts have not been provided with the resources to meet these considerable potential demands;
- in Northern Ireland there is a lack of detailed guidance for those acting as appropriate adults;
- there has been insufficient training for staff acting in the role of appropriate adult; and
- an appropriate adult may be a parent, guardian or relative or other person responsible for the care or custody of the person who is suspected of suffering from mental disorder. However, concerns have been expressed that relatives and carers may not be best placed to represent the interviewee.

Recommendation

14. The DHSSPS in partnership with Criminal Justice Agencies should establish a group comprising representatives of all the relevant stakeholders to review the appropriate adult scheme. The group should consider the effectiveness, efficiency and practical working of the scheme, including the criteria invoking the use of appropriate adults.

Assessment and Management of Mentally Disordered People in Police Stations, Including Those with Behaviour Disorder

3.23 Joint protocols should be developed for the arrangements to assess and manage mentally disordered people in police stations. Particular problems can arise with individuals whose behaviour is disturbed, for example those who are violent or who harm themselves. These behaviours may be related to factors such as intoxication, negative attitudes towards the police or emotional distress at the circumstances that have brought the individual to the police station. Such behaviours do not automatically or necessarily indicate the presence of mental disorder that requires admission to a psychiatric hospital. Behaviourally disturbed individuals may also have physical health needs, but nurses and other staff in Accident and Emergency departments understandably do not feel they should be subjected to violence or abuse. Police officers are not trained as nurses and there are very real concerns that someone may become seriously ill or die in police custody despite the efforts of those concerned to help them. The safe and appropriate care of such individuals is a major challenge. At present each case is dealt with on an individual basis, but there remain concerns that the situation is unsatisfactory.

3.24 In Queensland, Australia, Mullen and Chettleburgh (2002)[8] recognised a similar problem and recommended liaison between police and health services and consideration of a short-term assessment and detoxification centre co-located with a general hospital. The Review recommends that there should be discussions between the relevant stakeholders to consider the services that should be put in place and to ensure that agreed protocols are developed for the management of intoxicated and disturbed individuals in each locality.

Recommendations

15. Commissioners should commission services for the safe assessment, treatment and care of mentally disordered offenders in police stations.

16. Service providers and other stakeholders should agree joint protocols for the assessment and management of mentally disordered people in police stations, including those whose behaviour is disturbed.

Advice to Police

3.25 Where it appears to police that a person is suffering from mental disorder and that he or she has committed a minor criminal offence, police may exercise their discretion not to proceed further with the matter. Offending behaviour may be a manifestation of a relapse in illness and require treatment or it may be that the most appropriate response is for the individual to take responsibility for his or her behaviour. It is important that in such situations police should have ready access to advice from a suitably qualified health professional.

Recommendation

17. Commissioners should commission services that provide police with ready access to advice from suitably qualified health professionals.

Standard 5. Risk Assessment and Management

3.26 There are many risks associated with mentally disordered people in police stations. A co-ordinated risk assessment and management framework should be developed that extends across the Criminal Justice System and the HPSS. This should include the assessment of both individual and organisational risks and the development and implementation of risk management strategies. Key stakeholders should be involved in the development and implementation of this framework, including its application to the assessment, treatment and care of mentally people in police stations.

Recommendation

18. The DHSSPS in partnership with Criminal Justice Agencies should establish a group comprising relevant stakeholders to develop a risk assessment and management framework that extends across the Criminal Justice System and the HPSS and that applies to mentally disordered people in police stations.

Standard 6. Quality Assurance

3.27 In view of the potentially high vulnerability of mentally disordered people in police stations it is essential that quality standards are developed and audited.

Recommendation

19. The relevant regional body with responsibility for assuring the quality of mental health and learning disability services must ensure that quality standards are developed for mental health and learning disability services in police stations and that services are audited and subject to external independent inspection.

Standard 7. Mental Health Promotion and Education

3.28 People are often brought to police stations at times of crisis in their lives, for example a pattern of substance abuse may bring individuals into conflict with the law and may cause them to re-evaluate their behaviour. These occasions may, therefore, represent opportunities for the promotion of good mental health. Brief, but timely intervention may itself have therapeutic effect or it may direct the individual to another source of help where his problems can be addressed in more depth. A number of so-called arrest referral schemes have been established[9]. There are two main approaches. In one, police officers provide information about drug and other relevant services to those who have been arrested. In the other, mental health staff have access to prisoners in custody suites and provide either an assessment on site or at a subsequent meeting.

Recommendation

20. Service commissioners and providers should liaise with the regional body with responsibility for mental health promotion to identify opportunities for mental health promotion within police stations and ensure that appropriate services are provided and their impact evaluated.

Standard 8. Information, Research and Innovation

3.29 Detailed information was gathered on the functioning of the MDO Scheme[4]. There remains a need for basic epidemiological research and also for gathering information on the functioning and efficacy of mental health and learning disability services to police stations.

3.30 Information systems are currently being developed within the HPSS. These developments should take account of the need to provide health and social services to people in police stations.

Recommendations

21. The DHSSPS should ensure that research programmes are commissioned to examine the efficacy of different models of services to mentally disordered offenders in police stations with a view to informing further service planning.

22. The DHSSPS should ensure that development of Information Systems within the HPSS takes account of the need to provide health and social services to people in police stations.

Standard 9. Recruitment, Retention and Developing a Skilled Workforce

3.31 Service planning should consider the workforce requirements to deliver services to mentally disordered people in police stations. Training needs assessment should consider the needs of all stakeholders including, police, FMOs, lawyers and health and social services staff.

Recommendations

23. The DHSSPS in partnership with Criminal Justice Agencies should ensure that an assessment is undertaken of the learning and development needs of stakeholders including police, FMO's, lawyers and health and social services staff.

24. Appropriate training strategies should be devised and implemented to meet the identified needs for both induction training and for continuing professional development.

Standard 10. Sustainable and Transparent Funding

Recommendation

25. The development and maintenance of services for mentally disordered people in police stations across the province requires appropriate funding from the relevant sources. Funding should be delivered in accordance with a long term plan that ensures sustainable development of services. Funding arrangements must support the joint co-ordinated planning and delivery of services. There must be mechanisms that demonstrate that monies made available to services have reached their intended targets.

CHAPTER 4

BAIL

INTRODUCTION

4.1 A person may be released on bail by police after being charged with an offence or may be granted bail by a court. Mentally disordered offenders have the same rights as others to be considered for bail. Conditions may be attached to bail such as residence in an approved bail hostel.

CURRENT SERVICES

4.2 There are no specific services for those on bail with mental health problems. It is assumed that most service users obtain mental health services through primary and community services, both statutory and non-statutory.

NEEDS ASSESSMENT

4.3 There is a lack of information on the mental health problems experienced by those on bail, how effectively they avail of services and how effectively these services meet their needs. Some mentally disordered prisoners are granted bail subject to certain conditions such as having appropriate accommodation. Inability to meet such conditions may result in the individual having to remain in custody . Anecdotal evidence suggests there is a lack of suitable accommodation available for mentally disordered people who have been granted bail, leading to unnecessary imprisonment. In particular the provision in the community of a wider range of bail facilities with joint input by Criminal Justice staff and health and social services staff could offer different levels of supervision and therapy. Such facilities may be suitable for people with various mental health and learning disability problems including personality problems and alcohol and substance misuse problems. These could have the potential to significantly reduce the numbers on remand in prison. Facilities of this type may also be suitable for step-down of pre-release sentenced prisoners. At present, however, it is unknown how many mentally disordered people could be placed in such statutory services.

APPLICATION OF STANDARDS

4.4 In view of the lack of information on mentally disordered people on bail and the lack of specific services, the 10 Standards identified in Chapter 2 have not been considered in detail. As information becomes available and services develop the standards should be taken into full account.

Recommendation

26. The Northern Ireland Prison Service (NIPS) should commission research on the feasibility of reducing the number of mentally disordered people in prison by providing a broader range of facilities in the community. The research should address the mental health and social needs of male and female remand prisoners as well as the requirements of the Criminal Justice System. It should consider the potential utility of facilities with joint input by Criminal Justice staff and health and social services staff to offer different levels of supervision and therapy for a wide range of mental disorders including mental illness, learning disability, personality disorders and alcohol and substance misuse.

CHAPTER 5

COURTS

INTRODUCTION

5.1 Services are required at court to:

- identify and assess the needs of people who are suspected or confirmed as suffering from mental disorder;
- offer appropriate support, treatment and care to service users;
- provide appropriate information and support to carers; and
- advise the Criminal Justice System, where appropriate on the implications of the service user's condition.

CURRENT SERVICES

5.2 The MDO Scheme operates an open referral system and provides assessment and advice in Belfast Magistrates Court. There is no similar service to other courts in Northern Ireland.

5.3 McCall[1] found that user and carer views were generally positive in relation to the MDO Scheme, particularly in relation to solicitors and judges having an understanding of mental illness although some views were expressed that few solicitors had experience in dealing with mental health issues.

5.4 There is no formal psychiatric liaison service to the courts in Northern Ireland, nor any duty psychiatrist service to provide urgent assessments. Most psychiatric and psychological reports are requested by solicitors acting for the defence and only a few reports (0-5 reports *per annum* in Northern Ireland) are requested directly by the courts. Concerns have been raised that reports prepared on behalf of the defence may be limited in a number of respects, for example the remit given to the author of the report may be restricted and the report may not include important details such as the risks associated with any identified mental disorder. In many cases the author of the report may make recommendations in relation to the management of the offender but assumes no responsibility for providing services. Concerns have also been raised that the advice offered to the courts appears to be of variable quality.

5.5 Article 22 of the Criminal Justice (Northern Ireland) Order 1996[10] states that in any case where the offender is or appears to be mentally disordered, the court shall obtain and consider a medical report before passing a custodial sentence other than one fixed by law. It is not known whether the current systems effectively identify those suffering from mental disorder. Article 22 (5) requires that the report is prepared by a medical practitioner approved for the purposes of Part II of the Mental Health (Northern Ireland) Order 1986[11].

5.6 There are concerns that certain potentially useful court disposals are substantially under-used, such as probation orders with conditions of psychiatric treatment (Chapter 7 - Probation).

5.7 The international literature on the prevalence of mental disorder among those appearing before the courts is very limited and probably has little direct relevance to the current situation in Northern Ireland[1].

5.8 Birmingham (2001)[9] reviewed psychiatric court liaison schemes in England and Wales and concluded that the following were features of successful schemes:

- owned by mainstream general or forensic services;
- staffed by senior psychiatrists;
- nurse-led and closely linked to local psychiatric services;
- good working relationship with magistrates and the prosecution;
- good methods for obtaining health, social services and criminal records;
- access to suitable interview facilities;
- use of structured screening assessments;
- direct access to hospital beds;
- ready access to secure beds; and
- access to specialised community facilities.

APPLICATION OF STANDARDS FOR THE DEVELOPMENT AND DELIVERY OF FORENSIC SERVICES

5.9 The lack of information on mental health and learning disability services to the courts and the paucity of court liaison services means that it is difficult to apply the full detail of the standards identified in Chapter 2 to the existing services. However, the standards can still serve to guide future service developments.

Standard 1. A Co-Ordinated Joint Strategic Approach

5.10 While there is some information available on the MDO Scheme in Belfast, little is known about the efficiency or effectiveness of the current systems in the remainder of courts in Northern Ireland as regards their capacity to detect mental disorder or arrange appropriate services to meet the needs of mentally disordered people. There is a need to study these arrangements and to consider the strategic options that would be suitable for the courts.

5.11 It is a fundamental principle of this review that people who are subject to the Criminal Justice System should have equity of access and provision of services. Thus health and social services commissioners must commission a full range of statutory, voluntary and community sector mental health and learning disability services to meet the needs of mentally disordered people attending courts. Providers of community mental health and learning disability services must ensure they provide equity of access and provision of services for people attending courts.

5.12 It is expected that as mental health and learning disability services are developed for offenders, the courts will increasingly wish to receive information primarily from those who are involved in assessing and treating the individual. As mental health and learning disability services develop increased capacity the Court Service may wish to make service level agreements with health and social services providers to include, for example the provision of assessments, the availability of staff to act as appropriate adults and the provision of training to court staff.

Recommendations

27. Service commissioners should commission a full range of statutory, voluntary and community mental health and learning disability services to meet the needs of mentally disordered people attending courts.

28. Providers of community mental health and learning disability services should ensure they provide equality of access and provision of services for people attending courts.

29. In Year 5, when forensic mental health and learning disability services in Northern Ireland have increased in size and capacity, a detailed option appraisal should be undertaken to consider the provision of assessments and other services for the courts by alternative means, including by service level agreements.

Standard 2. Evidence, Principles and Purposes

5.13 Future court liaison schemes should be developed in response to assessed need. They should have explicit purposes and operate in accordance with agreed principles.

Standard 3. Organisational Structures and Interconnections

5.14 There is a need to ensure that there is appropriate liaison between courts and mental health and learning disability services. At present mentally disordered prisoners may be discharged at court without the necessary arrangements being made to ensure the provision of services in the community. This issue is considered further in Chapter 6 – Prisons.

Standard 4. Comprehensive and Accessible Services

5.15 The following issues have arisen in relation to current court procedures:

- Fitness to Attend Court;
- Prisoners Attending Court; and
- Court Procedures.

Fitness to Attend Court

5.16 Psychiatrists and others may find themselves being asked whether a witness in a criminal case is fit to attend court. There are established legal criteria to assist doctors in determining whether an accused person is fit to plead at court or fit to be tried. In practice these legal criteria may cause difficulties for doctors because there is little guidance on their exact medical meaning. However , there are no legal criteria at all to assist a doctor in determining whether a person is fit to attend court to give evidence. In Chapter 4 it was recommended that guidance should be developed on the assessment of fitness for interview in a police station and related matters. It would seem appropriate for the issue of fitness to attend court to be considered as part of that same process.

Recommendation

30. The DHSSPS in partnership with Criminal Justice Agencies should establish a group of relevant stakeholders to produce guidance on the assessment of fitness to attend court.

Prisoners Attending Court

5.17 Not infrequently, prisoners who are attending court complain of medical symptoms and ask to see a doctor. It can be difficult for doctors in such situations to know how to respond to the individual' s complaints, particularly when the doctor does not have access to the healthcare records held in prison. A system should be devised whereby doctors placed in this situation can have appropriate access to the relevant information.

Recommendation

31. Service providers must ensure that healthcare staff assessing and treating prisoners attending court have ready and appropriate access to existing healthcare information

Court Procedures

5.18 The procedures for the making of certain mental health disposals such as hospital orders involve the co-ordination of a number of different elements such as ensuring there is the requisite written or oral evidence from two appropriately qualified medical practitioners, ensuring that the receiving Trust has been given an opportunity to make representation to court and that a suitable place is available in hospital. In practice difficulties often arise because one or more of the necessary elements is missing or delayed.

5.19 Concern has also arisen that on a number of occasions individuals have continued to be treated in hospital as if they remained the subject of a Restriction Order , yet the court had dealt with the legal case and terminated the Restriction Order, but this information had not been communicated to the Responsible Medical Officer.

5.20 There is also a need to review policies and procedures in relation to escorting service users between court and mental health and learning disability facilities, including the use of video link facilities.

Recommendation

32. The DHSSPS should establish a group with the Court Service and other relevant stakeholders to review and develop procedures and protocols in relation to mentally disordered offenders to ensure efficient and effective operation.

Standard 5. Risk Assessment and Management

5.21 The courts often require information in relation to the assessment and management of risk related to mental disorder. There is a need to develop accredited standards in relation to risk assessment and management. This issue is discussed further in Chapter 11.

Standard 6. Quality Assurance

5.22 Court liaison schemes should develop robust performance, quality assurance and clinical governance mechanisms.

5.23 Secure inpatient forensic services should develop joint protocols and procedures in relation to escorting service users to and from court. These should be subject to audit.

Recommendation

33. The relevant regional body with responsibility for assuring the quality of mental health and learning disability services should ensure that quality standards are developed for mental health and learning disability services in courts and that services are audited and subject to external independent inspection.

Standard 7. Mental Health Promotion and Education

5.24 The MDO Scheme provides an opportunity to promote mental health among mentally disordered offenders. Future court liaison schemes should incorporate mental health promotion.

Recommendation

34. Service commissioners and providers should liaise with the regional body with responsibility for mental health promotion to identify opportunities for mental health promotion at courts and ensure that appropriate services are provided and their impact evaluated.

Standard 8. Information, Research and Innovation

5.25 Further information is required about the mental health needs of people attending court.

5.26 The use of technology such as video-links may help reduce the number and expense of escorted visits to court by service users in secure forensic services.

Standard 9. Recruiting, Retaining and Developing a Skilled Workforce

5.27 There is a need to provide interagency training that ensures that staff working in the health and social services have a good understanding of court procedures and that staff in the court service understand the needs, and respond appropriately to, individuals suffering from mental disorder.

Recommendations

35. The DHSSPS in partnership with Criminal Justice Agencies should ensure that an assessment is undertaken of the learning and development needs of stakeholders including court staff, lawyers, judiciary and health and social services staff.

36. Appropriate training strategies should be devised and implemented to meet the identified needs for both induction training and for continuing professional development.

Standard 10. Sustainable and Transparent Funding

Recommendation

37. The proposed review of options for mental health and learning disability services to the courts should include consideration of funding mechanisms.

CHAPTER 6

PRISONS

INTRODUCTION

SERVICE USERS AND CARERS AND THEIR NEEDS

6.1 It is a major challenge to provide effective healthcare within a prison environment. Life in prison is very different from life in the community or in hospital[12]. Many prisoners have emotional difficulties and may have been subjected during their earlier lives to trauma and neglect. In adult years they may have difficulty coping, have impaired relationships and poor integration into society arising from underlying personality difficulties or disorders. Alcohol or other substance misuse, self-harm and frequent previous contact with mental health and learning disability services are common.

6.2 Imprisonment inevitably entails loss of liberty , autonomy and right to self-determination. Some prisoners will experience withdrawal from substances they had previously abused or they may be exposed in prison to further substances of abuse. Prisoners may find themselves placed in the company of others they would not normally choose and they may be subject to bullying and harassment, perhaps from sectarian, paramilitary or racist elements. They may find particular difficulty coping with loss of contact with their families and children and they may find themselves lonely and isolated. Prisoners will also have to deal with the stresses related to the circumstances that have placed them in prison, including, for those not yet sentenced, the uncertainty of their disposal at court. Some may find that imprisonment provokes them to examine their previous lifestyle and the behaviours that led to their imprisonment and they may experience a range of emotions including anger, guilt, remorse or self-pity.

6.3 Understandably, most inmates resent being in prison. There is a lack of purposeful and satisfying activities and many prisoners are confined to their cells for prolonged periods. The high turnover of prisoners may make it difficult to establish supportive relationships with other inmates. It can also be difficult for staff and inmates to establish constructive relationships with each other. Staff may feel their systems of working do not support the development of such relationships and they may not feel adequately trained or supported. It can be difficult for staff to maintain good morale. Staff may consider the difficulty of their job is not appreciated or understood by wider society and that they may be too easily subjected to criticism. Some staff may reflect the antagonistic views towards prisoners that can readily be found elsewhere in our society.

6.4 Carers also experience a range of emotions and difficulties related to imprisonment. Relationships are often strained and carers may feel excluded.

6.5 McClelland and colleagues conducted a Review of Non-natural Deaths in Northern Ireland Prison Service Establishments (2005)[13]. They identified unique features of the Northern Ireland Prison Service (NIPS) in 2004. These included the separation of paramilitary affiliated prisoners; the threats, attacks and murder of staff during the course of the

Troubles; the severe industrial relations climate; antiquated staffing practices in comparison to other UK prison systems; high staff to prisoner ratios and the apparent parochial nature of the prison service. They considered that the management of vulnerable prisoners was not high enough on the agenda of NIPS and that the prison regimes appeared to be over controlled and therefore negatively impacting on the mental health and care of vulnerable offenders.

6.6 McClelland and colleagues also noted that since the reviews in 2004 a number of relevant initiatives had been taken and commitments to action made by both NIPS and DHSSPS. These developments were welcomed by the McClelland Committee.

6.7 This chapter examines in more detail the needs of mentally disordered adult prisoners. Improvement of the mental health of prisoners must comprise 2 elements: both

- creation of a prison environment that actively promotes mental health; and

- provision of a range of mental health and learning disability services.

6.8 These elements must be delivered by a partnership between NIPS and the HPSS which supports a joint co-operative approach. In addition to measure to promote mental health, prisoners require regular input from primary care services, general adult psychiatry, learning disability, psychotherapy, forensic services, adolescent and addiction services. Additional recommendations are made in Chapter 10 in relation to learning disability services. Chapter 11 also elaborate on services for women, people suffering from personality disorder and from Autistic Spectrum Disorder and also the assessment and management of risk. Recommendations are also made in the reports by the Alcohol and Substance Misuse Committee and the Child and Adolescent Mental Health Committee which are relevant to people in prison.

CURRENT SERVICES

The Prison Estate

6.9 The prison state in Northern Ireland comprises:

- Maghaberry;
- Magilligan;
- Hydebank Wood;
- Prison Service College, Millisle; and
- Prison Service Headquarters.

6.10 Maghaberry is a high secure prison housing adult male long-term, sentenced and remand prisoners, both in separated and integrated conditions. Maghaberry also has responsibility for male immigration detainees who are accommodated in a facility at Belfast prison. The overall responsibility for immigration detainees rest with the Immigration and Nationality Department of the Home Office.

6.11 Magilligan is a medium security prison, housing shorter-term sentenced adult male prisoners. It also has low security accommodation for selected prisoners nearing the end of their sentence who are being prepared for return to the community.

6.12 Hydebank Wood is a young offenders centre and prison for male remands and sentenced young offenders between the ages of 17 and 21, in some circumstances up to age 23, and all female prisoners including young offenders and female immigration detainees. Sometimes young offenders under 17 are sent to Hydebank because of the lack of services elsewhere.

6.13 The average daily population in the Northern Ireland prisons has varied considerably over the past 35 years and currently is close to 1,400 with a total throughout per year of approximately 5,000. Further details can be found at www.niprisonservice.gov.uk

Mental Health in Prisons

6.14 Mental health problems, and mental illness, are the most prominent single health challenge in the prison environment. In a recent study by Blaauw 2004[14], an estimated 63% of prisoners had a psychiatric disorder, compared with 16% of the general population. These disorders included affective disorders, anxiety, psychosis, alcohol and substance misuse and personality disorder. Although no comprehensive similar study has been carried out in Northern Ireland, the evidence suggests that if anything the figure is even higher. There is an urgent requirement for detailed assessment of mental health needs of prisoners in Northern Ireland.

CURRENT MENTAL HEALTH AND LEARNING DISABILITY SERVICES IN NORTHERN IRELAND PRISONS

6.15 In Northern Ireland prisons, primary care services are provided by nurses, healthcare officers and medical officers (who are mostly general practitioners) who refer to secondary psychiatric and psychological services. Prisoners undergo an initial nursing and medical assessment on committal to prison and those with identified mental health problems are referred for comprehensive mental health nursing assessment. Prisoners may subsequently refer themselves or be referred to a range of mental health care services.

6.16 Specific provision is made for mental health services by sessions from a Forensic Psychiatrist, a General Adult Psychiatrist with an interest in substance misuse, two recently appointed Mental Health Nurse Therapists, an Occupational Therapist from an HSS Trust, and from mental health nurses and psychologists employed by NIPS. Counselling services are provided by voluntary organisations such as the Samaritans and are accessed by a confidential phone line. A listener service has been established in Magilligan.

6.17 Prisoners receive treatment in normal prison location and in prison healthcare centres. There is an inpatient psychiatric unit in Maghaberry. Prisoners with mental illness or severe mental impairment may be transferred to health service facilities under the provisions of the Mental Health (Northern Ireland) Order 1986[11]. There are, however, legal problems which currently make it impossible to transfer unsentenced prisoners to high secure hospitals. Moreover, there are no dedicated treatment facilities for prisoners with personality disorders.

6.18 One of the key areas of recent development in NIPS has been the development and implementation of the Multi-Agency Prisoner Resettlement Strategy . A key issue in the Strategy is 'Promoting a healthier and pro-social lifestyle'. This will involve agencies within and out, with the prison working in close partnership to address issues which impact on mental health and well-being such as housing and employment.

SERVICE DEVELOPMENT

6.19 Various reviews have contributed to the growing body of evidence and opinion that prison healthcare should no longer be the sole responsibility of the NIPS:

- Review of the Provision of Healthcare Services to Prisoners (2002)[15];
- Healthcare Needs Assessment (2004)[16];
- Human Rights Commission Report on Women Prisoners (2004)[17];
- HM Inspector of Prisons and the Chief Inspector of Criminal Justice in Northern Ireland Report on Female Prisoners at Ash House, Hydebank Wood Prison (2004)[18]; and
- Review of Non-natural Deaths by Professor McClelland and colleagues (2005)[13].

6.20 The Review of the Provision of Healthcare Services to Prisoners 2002[15] stated that it was satisfied that healthcare standards in Northern Ireland prisons were broadly comparable to those in prisons elsewhere throughout the United Kingdom.

6.21 Since 2000, Her Majesty's Prison Service and the Department of Health in England have been working in formal partnership to improve health services for prisoners[19], culminating in the transfer of commissioning responsibility for those services to the NHS.

6.22 In the light of this, and the various Review recommendations, the then Health and Prisons Ministers accepted a joint NIPS and DHSSPS submission in April 2005 recommending the transfer of lead responsibility for prisoner healthcare from the NIPS to the DHSSPS by April 2007. A project management framework has been established with responsibility to achieve this objective, taking account of the needs of Northern Ireland prisoners and experience in other jurisdictions. This transfer is thus an important development with major implications for DHSSPS and for the NIPS.

STANDARDS

Standard 1. A Co-ordinated Joint Strategic Approach

6.23 Many of the organisational difficulties experienced over the years in attempting to provide healthcare within the prison environment have been related to the separating of prisoners from the health services in the rest of the community and to the creation of separate health services for prisoners. The transfer of responsibility to DHSSPS should help ensure that prisons are not viewed as being separate from the communities in which they are situated.

6.24 The decision to transfer responsibility is fully consistent with the principle of this Review that people subject to the Criminal Justice System should have equity of access and provision of services. There are many potential advantages to this arrangement, for example it should offer to prisoners the full range of statutory, voluntary and community sector services available in the community, including assessment and treatment services. It should assist information sharing, ensure that services come under similar quality assurance and governance arrangements and facilitate the use of shared risk assessment and management systems and the extension of Health and Social Services information technology services to prisoners. It should support common approaches to research, to workforce planning, staff training and development.

6.25 It is essential that these arrangements for service provision are taken forward jointly by NIPS and DHSSPS working in partnership. Commissioners of services must understand the needs of people within prison environments and service providers must be enabled to develop sufficient capacity to provide the full range of services required. Services must work together in an integrated manner to meet the needs of service users and carers. There must be robust quality assurance mechanisms including independent external review.

6.26 The Review recommends that planning the future of mental health and learning disability services for prisoners is integrated with the planning of mental health and learning disability services throughout Northern Ireland, including the joint strategic approach co-ordinated by the Regional Forensic Network.

Recommendations

38. Improvement of the mental health of prisoners requires a partnership between the DHSSPS and the NIPS to ensure:

    - development of a prison environment that actively promotes mental health and well-being; and
    - provision of a comprehensive range of mental health and learning disability services which address the needs of prisoners and are integrated with other community and prison services to ensure effective through care.

39. The Review welcomes the decision to transfer responsibility for the healthcare of prisoners to DHSSPS and emphasises that it must be supported by robust quality assurance mechanisms and by sufficient resources to meet the needs.

40. The Review recommends that planning the future of mental health and learning disability services for prisoners is integrated with the planning of mental health and learning disability services throughout Northern Ireland including the joint strategic approach co-ordinated by the Regional Forensic Network.

Standard 2. Evidence, Principles and Purposes

Assessment and Monitoring of Need

6.27 Effective service planning requires detailed information in relation to the needs of prisoners and their carers. This is an essential component of the project overseeing the transfer of responsibility. The assessment of need must take account of the full range of mental disorders. It should also consider the need to support the work of criminal justice staff, for example, by assessing and providing appropriate treatment and care for people engaged in offending behaviour programmes.

Recommendations

41. The joint DHSSPS/NIPS project to transfer responsibility must ensure that a detailed assessment of the needs of mentally disordered prisoners and their carers is completed by the end of 2006. The assessment of need must encompass all those suffering from mental disorder including mental illness, learning disability, personality disorder and alcohol and substance misuse. It must take full account of the resources required by health and social services staff to work co-operatively in support of criminal justice staff.

42. The needs assessment must lead to the provision for service commissioners of systems to monitor and evaluate in an ongoing manner the needs of service users and carers and the impact of services on need.

Values, Principles, Culture and Ethos

6.28 The Review recommends that, following joint consultation, explicit values and principles are agreed for prison mental health and learning disability services that link with those for other prison staff and community health services. These values and principles should guide the creation of prison environments that promote mental health and they should also guide the development and delivery of mental health and learning disability services. It will be essential that these values and principles are developed jointly by the DHSSPS and by the NIPS and that they are placed at the heart of all developments to promote mental health within the prison environment and to deliver a range of mental health and learning disability services. Thus the principles and values should form the centre of induction and training for all staff and they should be translated rigorously into the day-to-day activities of the services to help create a culture and ethos that supports mental well-being.

Recommendations

43. The DHSSPS and NIPS in partnership should develop explicit values and principles for mental health and learning disability services and Criminal Justice Services for prisoners that guide the development of a prison environment that actively promotes mental health and well-being and that provides a comprehensive range of mental health and learning disability services.

44. The DHSSPS and NIPS in partnership should agree arrangements to develop strong and cooperative working relationships between prison staff, health and social services staff, and Criminal Justice Agencies at operational and managerial levels. These should include the supporting organisational structures, training and the development of joint policies, protocols and procedures.

Involvement of Service Users, Carers and the Provision of Advocacy

6.29 The principles of this Review require the involvement of service users and carers in service development and delivery. There is also a need for the provision of advocacy services.

6.30 Those who currently advocate for service users include legal representatives, the Prisoner Ombudsman, members of the Independent Monitoring Boards, chaplains, probation officers, mental health and learning disability service providers and others. Advocacy services and complaints procedures can be an important safeguard for service users and a driver for change in attitudes, practice and culture. These services are an essential component of in-reach mental health and learning disability services.

Recommendations

45. Commissioners of mental health and learning disability services in prisons must ensure that service users and carers are involved in the development, delivery and monitoring of services.

46. Commissioners of mental health and learning disability services in prisons must ensure that advocacy services and complaints procedures are developed for service users in prisons, building on those already in place.

Standard 3. Organisational Structures and Interconnections

6.31 Organisational structures must support the delivery of the full range of mental health and learning disability services in a multi-disciplinary and interagency manner. Regular input is required from statutory, voluntary and community sector providers of forensic, adult mental health, alcohol and substance misuse, learning disability and adolescent services with ready access to other mental health services that are more specialised or less frequently required. Services must be configured in ways that support key objectives, for example, there should be close linkages between Maghaberry and the regional secure unit to support the early identification of prisoners who require inpatient treatment in conditions of medium security and to facilitate their transfer at the earliest possible opportunity There should be linkages between prison and the community that maximise continuity of treatment, care and support. It is essential that these services are planned carefully by the transfer project in a coherent and strategic manner rather than being allowed to develop in an in an unco-ordinated way. They will require consultation and co-ordination with a wide range of service providers.

6.32 The DHSSPS has published guidance on “Discharge from Hospital and the Continuing Care in the Community of People with a Mental Disorder who could Represent a Risk of

Serious Physical Harm to Themselves or Others" (May 2004)[20]. Paragraph 12 states that when a person suffering from mental disorder, including personality disorder and who could represent such a risk, is discharged from prison a clear duty rests with NIPS to ensure that the relevant Health and Social Services Trust is notified so that arrangements for the service user's care in the community can be put into effect without delay. However, currently there are not sufficiently detailed information systems, nor are there enough services in the community, particularly for those suffering from personality disorder, to be satisfied that there are adequate arrangements to provide appropriate support, treatment and care for mentally disordered prisoners on their discharge from prison.

Recommendation

47. The project overseeing the transfer of lead responsibility must ensure that joint working arrangements with all relevant mental health and learning disability service providers are agreed and published before April 2007. It must be demonstrated that service providers have sufficient resources and capacity to meet the identified needs, including the needs of prisoners and discharged prisoners who are suffering from mental illness, learning disability, personality disorder and alcohol and substance misuse. The arrangements must take full account of the resources required by health and social services staff to work co-operatively in support of criminal justice staff in relation to prisoners and discharged prisoners.

Standard 4. Comprehensive and Accessible Services

Assessment on Committal to Prison

6.33 Assessment of the physical and mental state and the needs of each individual on committal to prison is conducted by nurses and medical officers. Professor McClelland and colleagues (2005)[13] in a report on six non-natural deaths in prison have identified a number of improvements that need to be made to the process of receiving prisoners into custody and assessing their health needs. The Review fully supports those recommendations. The NIPS is implementing a Practice Development Programme at Maghaberry with support from the Royal College of Nursing and the University of Ulster to improve committal services. The transfer project should ensure that these changes continue and are further developed as necessary following transfer of responsibility.

Recommendation

48. The Review supports the recommendations made by Professor McClelland and colleagues (2005)[13] in relation to the assessment, treatment and care of prisoners on committal to prison. The transfer project should ensure that work continues as quickly as possible to address these recommendations and that arrangements are made to complete any outstanding work following transfer of responsibility.

Assessment and Management of People Suffering from Personality Disorder

6.34 Personality disorder is a major issue for the NIPS, the wider Criminal Justice System, the HPSS and for society generally. A full range of appropriate interventions is required. Services should be evidence-based. Where there is inadequate evidence on the effectiveness, research should be incorporated into services to add to the available evidence. The Review recommends that the following services should be developed:

- a range of therapeutic interventions, including the development of therapeutic community approaches, both in secure settings and in the community;
- day patient and outpatient services provided by forensic and other mental health and learning disability services; and
- input from forensic and other mental health and learning disability services to the assessment and management of prisoners attending offender behaviour programmes.

6.35 The services required for prisoners suffering from personality disorder are considered further in Chapter 11, but the following recommendations are made here:

Recommendations

49. Commissioners of mental health and learning disability services for prisoners must ensure that services provide assessment, treatment and care for all people suffering from mental disorder including those suffering from personality disorder.

50. DHSSPS should take the lead in developing, in partnership with the Criminal Justice Agencies, an inclusive model of assessment, treatment and care of people suffering from personality disorder.

Healthcare Centres and Mentally Disordered Prisoners

6.36 There are healthcare centres in each prison establishment which admit prisoners with physical and mental healthcare needs, including people with complex mental health needs who have been accepted and are awaiting transfer to a high or medium secure hospital. However, some patients with mental disorders who are admitted to these units would not meet the criteria for admission to a psychiatric hospital; instead, if they were outside prison, they would receive treatment and care in the community. It appears that some prisoners could be supported in ordinary prison location by in-reach mental health services working in partnership with prison staff.

6.37 The Review considers that a range of measures including diversifying ordinary prison accommodation, supporting mentally disordered prisoners in ordinary location and rapidly transferring to secure inpatient services those who require such placement may provide more appropriate services to service users and also reduce the need for places in healthcare centres. Over the years prisons have found the healthcare centre environment useful in the management of people suffering from a wide range of disorders such as those undergoing detoxification from drugs and alcohol, those suffering from stress reactions and other neurotic disorders and those awaiting transfer to outside hospitals. As more appropriate services are developed, the need for health centre places and mental illness beds should be reduced, as in the Scottish Prison Service, although it is unlikely that the need for mental illness places could be eliminated altogether, at least not in the short term. It may also be appropriate to centralise the main healthcare centre facility in one establishment.

6.38 It is recommended that a specific mental health needs assessment is conducted to consider the needs of service users and the need for healthcare beds in prison.

Recommendation

51. A specific mental health needs assessment should be commissioned as part of the programme of the transfer of lead responsibility to examine the needs of service users who are placed in prison healthcare centres and the options for alternative services and placements. This should be completed by the end of 2006.

The Needs of Women Prisoners

6.39 Women prisoners often demonstrate high levels of mental health problems. For the small numbers of women prisoners with continuing behavioural disturbance there are particular needs for joint co-operative interagency working. It is imperative to identify better arrangements to provide alternatives to custody. The NIPS has commissioned an assessment of the needs of women prisoners. This should consider alternative placements including those at lower levels of security.

Recommendations

52. Services should be commissioned for women prisoners that are gender sensitive and that have the capacity to respond appropriately to the range of their mental health and learning disability needs, including substance misuse and personality disorder.

53. NIPS should commission a research project into alternatives to prison for mentally disordered women, including placements at lower levels of security.

The Needs of Young Offenders

6.40 The male and female young offenders' centres at Hydebank admit young offenders between the ages of 17 and 21 and these detainees may remain there until the age of 23. There is a need to ensure the provision of adolescent mental health and learning disability services to those who are under the age of 18 and to ensure the appropriate transfer to adult services of all relevant information and the treatment and care of individuals who attain the age of 18. Joint management plans should be agreed in the case of each individual suffering from mental disorder.

Recommendations

54. A full range of mental health and learning disability services including adolescent, psychotherapy and personality disorder, alcohol and substance misuse should be commissioned. Community service providers must ensure that a full range of co-ordinated services is developed and provided to those who are under the age of 18, and DHSSPS must play its part in ensuring adequate provision of the necessary expertise.

55. Service providers must develop protocols and procedures so that management plans are jointly agreed in the case of each adolescent suffering from mental disorder when transferring to adult prison services or healthcare services in the community.

On-call Services

6.41 The principles adopted by this Review require that there should be equity of access and provision of services to prisoners; there should therefore be formal on-call arrangements for each prison establishment to deal with out of hours mental health emergencies.

Recommendation

56. The transfer project team should define requirements and, together with service commissioners and providers, put such arrangements in place before April 2007.

Treatment Issues

6.42 Mentally disordered prisoners should have access to treatment and care from a range of statutory and voluntary services. In a prison environment certain circumstances arise that require further consideration.

(a) Providing treatment to mentally disordered prisoners who lack capacity

6.43 Most mentally disordered prisoners have the mental capacity to decide whether or not to accept any treatment that is offered to them. However, some prisoners may be suffering from or may develop severe mental disorder that renders them incapable of deciding whether or not to accept treatment. Such individuals should, if they satisfy the relevant criteria, generally be transferred to a HPSS hospital under the provisions of Part III of the Mental Health (Northern Ireland) Order 1986[11] ("the Order"). However, there may be delays in transfer caused, for example, by the difficulties in transferring remand prisoners to high security, the lack of availability of a bed in hospital or the delays inherent in current assessment and transfer procedures. The healthcare centres in the prison establishments are not recognised as hospitals under the Order, and people cannot be detained there and given treatment under the provisions of the Order. People who are suffering from severe mental disorder and who are not receiving appropriate treatment may pose a serious risk of harm to themselves or others. Such individuals may be treated under common law in emergency situations. Earthrowl and colleagues (2003)[21] have proposed guidance on providing courses of treatment to prisoners who lack mental capacity, however these measures do not negate the underlying imperative that such prisoners should be transferred to hospital.

6.44 The Review does not recommend powers to permit compulsory treatment of mentally disordered people in prison without their consent. The Review believes that such cases must be addressed by the provision of adequate resources and procedures that ensure timely transfer to hospital of those who require such treatment.

(b) Transfer of Prisoners to Inpatient Hospital Services

6.45 It should be noted that when a person outside of prison is suffering from severe mental disorder and requires admission to a psychiatric hospital he or she is generally admitted without delay, usually on the same day as the decision has been made to admit. The same standard should apply to prisoners.

6.46 When prisoners require transfer from prison to hospital to receive inpatient treatment for mental disorder they generally require secure inpatient services. There are gaps in current provisions resulting in unacceptable delays. At present mentally disordered prisoners remain in prison when they should be in hospital.

6.47 There are particular difficulties in obtaining inpatient treatment for mentally disordered prisoners who are on remand and who require treatment in a high security facility. These difficulties, and options to address them, have been considered more fully in Chapter 8 and by the Forensic Sub Committee of the Legal Issues Committee.

6.48 For those prisoners who require treatment in conditions of medium security it will be important to develop close working links between the prisons and the Regional Secure Unit and to ensure that high priority by management of the Regional Secure Unit is given to the transfer of prisoners. In order to ensure that places are made available to prisoners it will be essential to ensure that there are adequate long–stay medium secure places, low secure places and step-down facilities in the community.

Recommendations

57. People who require admission to hospital for assessment or treatment under the provisions of the mental health legislation must have equal access and priority whether they originate in prison or in the community. The application of this standard in practice should be subject to external audit by the appropriate health care inspection body.

58. The transfer project should ensure that specific joint working arrangements between service providers, the Prison Service and the DHSSPS are agreed and published before April 2007.

Standard 5. Risk Assessment and Management

6.49 There are currently no standardised risk assessment and management systems in routine clinical use in the mental health and learning disability services within the prisons. It is recommended that a multi-disciplinary and interagency operational group should identify policies and procedures. These policies and procedures should encompass risk assessment and management for service users in prison and also for the discharge of individuals to the community.

6.50 The operational group should also identify organisational risks and liabilities through its clinical governance mechanisms and should formulate and implement appropriate plans to address them.

6.51 The development of risk assessment and management systems for mentally disordered prisoners should proceed in consultation with criminal justice agencies, taking account of recent and proposed developments such as the extension of MASRAM to include violent offenders.

Recommendation

59. The DHSSPS in partnership with Criminal Justice Agencies should establish a group comprising relevant stakeholders to develop a risk assessment and management framework that extends across the Criminal Justice System and the HPSS and that applies to mentally disordered people in prisons. The framework must not discriminate unjustifiably against people suffering from mental disorder.

Standard 6. Quality Assurance

6.52 The Review has recommended the principle that services should be open, accountable and subject to external review. It is essential that the services available for mentally disordered people in prisons have robust clinical governance and internal quality assurance mechanisms and are subject to external independent inspection and review.

6.53 Measures of service quality may include assessment and monitoring of need, the capacity of the services to identify and respond to the needs of individuals with mental disorder, the capacity to transfer to outside hospitals those who require such treatment and the capacity to work in a joint interagency manner to address problems such as behavioural disturbance and offending behaviour.

6.54 It is also important to identify and remedy obstacles to performance such as delays for visiting staff in gaining access to prisoners and inadequate interview facilities.

6.55 Where adverse or untoward incidents or events occur, these should be investigated by methods, which not only establish the facts of what happened, but also examine the underlying processes, procedures and systems. The National Patient Safety Agency favours the use of root cause analysis in this regard. Robust mechanisms must be put in place to ensure there is learning from such incidents and that this learning is translated into relevant practical changes. Serious untoward incidents should be independently reviewed.

Recommendation

60. Mental health and learning disability services and Criminal Justice Agencies should develop joint co-ordinated interagency standards that encompass both the creation of a prison environment that promotes mental health and the provision of a full range of mental health and learning disability services. These standards should be supported by clinical governance arrangements, internal quality assurance mechanisms, external independent inspection and systems of learning from adverse events. NIPS and DHSSPS should jointly set up an effective operational group in 2006.

Standard 7. Mental Health Promotion and Education

6.56 The World Health Organisation (WHO) Regional Office for Europe produced a Consensus Statement on Mental Health Promotion in Prisons (1998)[22]. It recognised that although most mental disorders may have been present before imprisonment these disorders could also be made worse by the conditions of imprisonment and thus prison has the potential to cause significant mental harm. It agreed that the fundamental rights of prisoners entailed the provision of preventive treatment and healthcare equivalent to those provided in the general community, that the concept of care, positive expectations and respect should permeate all prisons and that the promotion of the mental well-being of prisoners and prison staff is vital in prisons. In addition to its detailed statement, the WHO also produced a management checklist to assist mental health promotion in prisons[23].

6.57 Health promotion initiatives are being undertaken jointly by the Prison Services and the National Health Service in Scotland[24] and in England and Wales[25]. The Healthcare Needs Assessment (2004)[16] recommended development of Health Promotion in the Northern Ireland prisons, and limited progress has been made.

6.58 It is essential that Health Promotion initiatives include specific measures to promote mental health and well-being that become instilled within the culture and ethos of the prison establishments. They cannot be seen as the sole preserve of Mental Health and Learning Disability Services, but rather they must be owned and led in partnership with the body with regional responsibility for mental health promotion, the wider health sector bodies and the Prison Service and developed in partnership with a range of users' and carers' representatives, voluntary and community sector and statutory Mental Health and Learning Disability services.

6.59 It is recommended that a Regional Prison Mental Health Promotion group is established that is centrally led and co-ordinated and that is sensitive to the circumstances of each prison establishment. This group should liaise closely with the regional body with responsibility for mental health promotion. The group should identify the needs in Northern Ireland and the efficacy of developments elsewhere and it should formulate and implement a range of proactive measures for prisoners as well as providing education, training and support for prison and healthcare staff. There should be evaluation of the impact of the group's activities.

Suicide and Other Self-Harm

6.60 Suicide and self-harm are major concerns in prison, as in the rest of society. Prisoners show high rates of mental health problems and are subject to the stresses related to offending behaviour and imprisonment. It is imperative to ensure that measures are put in place to address the identified suicide risks. The WHO[22] (2000) has produced guidance on the prevention of suicide in prisons. The Royal College of Psychiatrists (2002)[26] has published a Council Report on Suicide in Prisons, which made 26 recommendations and provided guidance on the assessment of prisoners. These include recommendations on resources, services, and procedures for assessment and staff training. Although the Report relates primarily to the situation in England and Wales, its recommendations are highly relevant to Northern Ireland.

6.61 The NIPS has introduced a suicide and self-harm policy in 2004, which has been a positive step. The report by Professor McClelland and colleagues (2005)[13] reviewed 6 non-natural deaths in prison prior to that policy and made additional recommendations which are supported by the Review.

Recommendation

61. The DHSSPS, involving the body with regional responsibility for mental health promotion, in partnership with NIPS, service providers and representatives of users and carers should establish a Regional Prison Mental Health Promotion group to address mental health promotion and suicide prevention. The group should build upon the existing policy and formulate a strategy that sets explicit standards. It should seek to establish a culture and ethos in the prisons that promotes mental health and well-being for prisoners and staff and that further reduces the risks of suicide. The goal should be for the initial strategy to be implemented by 2007. Work should continue in conjunction with the regional body with responsibility for mental health promotion and should include evaluation of its effects.

Standard 8. Information, Research and Innovation

6.62 In order to work in an efficient co-ordinated multi-disciplinary and interagency manner, mental health and learning disability services in the prisons must have comprehensive information strategies that include, for example, the gathering of information on need, service performance and quality. There is a need to develop Information Technology systems that are integrated with the HPSS systems and that support service delivery. Consideration should be given to co-ordination with relevant components of criminal justice information systems.

Recommendations

62. The transfer project should ensure that information systems are established before April 2007 to meet the needs of mentally disordered prisoners. Information systems for prisoners should integrate and evolve with the HPSS systems and should be developed, where appropriate, to integrate with criminal justice systems in support of joint working.

63. The DHSSPS should commission and promote ethically approved research in relation to the needs and services for mentally disordered prisoners, for example research should be undertaken into the needs for healthcare centre places, the transfer of prisoners to Health Service, bail and community step-down facilities, the efficacy of offender management programmes and the efficacy of mental health promotion strategies.

Standard 9. Recruitment, Retention and Developing a Skilled Workforce

6.63 Workforce planning strategies and processes that are supported by both the Health and Social Services and by the Criminal Justice System must support the development and maintenance of the required range of mental health and learning disability services. These must ensure the recruitment and retention of staff. There must also be Learning and Development arrangements to provide staff with the necessary knowledge, skills, support and opportunities for further learning and personal development. The needs for Learning and Development include not only staff working in prison mental health and learning disability services, but also other staff working in interconnecting health and social services and in criminal justice agencies. There is a need for interagency training to help promote understanding of the different, but interconnected roles. In addition service users and carers have learning and development needs that should be addressed. Consideration should also be given to the emotionally demanding nature of much of the work in prisons and the consequent needs of staff for psychological support.

6.64 There is a particular need, for all agencies, to develop expertise in the assessment and management of behavioural disturbance, personality disorder and offending behaviour. All of these services require close and co-operative working relationships between criminal justice staff, forensic and other mental health and learning disability services, supported by flexible working patterns, joint policies, procedures and protocols, agreed standards, joint research and audit, and shared learning and development. It is proposed that a Consortium is developed to bring together Criminal Justice Agencies, health and social services agencies and the prisons, to link community services and develop expertise in the psychotherapeutic aspects of assessment, therapy and risk management.

6.65 Learning and development mechanisms must be closely aligned to service development. Robust systems must be put in place to ensure there is learning from adverse incidents and that this learning is translated into relevant practical changes.

Recommendations

64. The DHSSPS must ensure that development and maintenance of services for mentally disordered prisoners are supported by robust workforce planning and provision of opportunities for staff to avail of learning, development and support.

65. Service providers must ensure that learning and development strategies for all staff are closely linked to service development and to governance arrangements.

66. A multi-agency consortium should be formed in 2006 to promote psychotherapeutic expertise in the assessment and management of behavioural disturbance, personality disorder and offending behaviour. The lead should be taken by DHSSPS with input from criminal justice agencies and the relevant health sector bodies.

Standard 10. Sustainable and Transparent Funding

6.66 The transfer of lead responsibility for prisoner healthcare to DHSSPS by April 2007 will include transfer of current funding from NIPS. In England the similar transfer of responsibility was accompanied by substantial additional funding (an increase of approximately 40%).

The current Review is highlighting major current under-funding of mental health and learning disability services throughout the HPSS and is recommending additional resources. Additional funding is highly likely to be required to ensure both the development of services on the basis set out in this Review and their effective delivery.

Recommendation

67. The strategic development of mental health and learning disability services for prisoners requires sustainable additional funding. Funding arrangements must support the joint co-ordinated multi-agency planning and delivery of services. There must be mechanisms that demonstrate that monies made available to services have reached their intended targets.

CHAPTER 7

PROBATION

INTRODUCTION

7.1 The Probation Board for Northern Ireland (PBNI) has a statutory responsibility for assessing and supervising offenders in the community in order to protect the public from risk of harm and to rehabilitate offenders. Many of these offenders have one or more mental health needs related to mental illness, learning disability, personality disorder and alcohol and substance misuse. There are, therefore, clear overlaps between the work of PBNI and mental health and learning disability services and thus, in accordance with the principles proposed in Chapter 2, there should be joint co-operative planning and delivery of services in order to best meet the needs of service users and carers. People who are on probation must have equity of access and provision of mental health and learning disability services.

7.2 This chapter considers the relationship between PBNI and mental health and learning disability services for adults with mental illness, personality disorder and learning disability and it makes recommendations for the future development of services. Additional recommendations in relation to learning disability are contained in Chapter 10 and further recommendations on specific issues including personality disorder, risk and the Multiagency Procedures for the Assessment and Management of Sex Offenders (MASRAM) are contained in Chapter 11. Interfaces with Alcohol and Substance Misuse Services, with Child and Adolescent Mental Health Services and with Legal Issues are addressed in the respective reports of this Review.

BACKGROUND

Probation Services

7.3 Since the introduction of the Criminal Justice (Northern Ireland) Order 1996, the offender population supervised by PBNI has not only increased, but the crime profile has shifted towards more serious, difficult and potentially dangerous and disturbed offenders. On 31 March 2005 PBNI supervised 1,253 Probation Orders, 804 Community Service Orders, 803 Custody Probation Orders and 31 Supervised Life Licensees. Probation staff conduct thorough risk assessments during each stage of contact with the offender, including the preparation of Pre-Sentence Reports, case management and programme delivery. Often this work is conducted in the absence of involvement of health and social services agencies. Sentences such as the Custody Probation Order (introduced 1 January 1998) have led to PBNI supervising offenders previously given custodial sentences.

7.4 During 2004/05 the courts requested 8,228 Pre-Sentence Reports from PBNI. A review in 2004 of Pre-Sentence Reports over a 6 month period found that 60% of these reports were written for offenders where the index offence was one of violence. More than half of those reports written on violent offenders were for an offence of Assault Occasioning Actual Bodily Harm or a more serious violent offence. In addition 42% of these offenders had 3 or more previous convictions, indicating a pattern of ongoing offending behaviour rather than an isolated incident. Some of these individuals were not engaged with or had been excluded from primary care, mental health and learning disability services, social services and housing authorities and were deemed unsuitable for safe supervision by probation alone. Concerns have been raised that such patterns of exclusion and marginalisation by services may be associated with increased risks of self harm and further offending.

7.5 There are also concerns that currently there are not sufficient mental health and learning disability services working with PBNI to contribute to assessment of individuals and their mental health needs, to advise criminal justice agencies and to arrange or provide treatment and care.

7.6 As regards supervision of offenders by probation, current standards require that offenders are supervised according to their likelihood of re-offending as well as the level of risk of harm they pose to the public. Offenders on community supervision orders are required to report to a probation officer in accordance with instructions and to notify any change of address. At 31 March 2005, PBNI managed 330 offenders in custody on Custody Probation Orders, which was one third of the prison population and 473 in the community Many of these offenders had committed serious offences of violence and sexual violence, and had previously had contact with psychiatric and psychological services. Many also had serious personality deficiencies and difficulties. However, there was a lack of joint working between PBNI and mental health and learning disability services. At 2005 there were 115 PBNI "listed cases" which were deemed to pose a high risk of potential harm to the public. Analysis of these cases indicated that one third had convictions of a sexual nature, including rape, unlawful carnal knowledge, gross indecency and abduction, one third had convictions for violence, including Assault Occasioning Actual Bodily Harm, Grievous Bodily Harm and use of a firearm and the convictions of the remaining one third included burglary, robbery, arson and motoring offences.

7.7 PBNI programmes are delivered throughout Northern Ireland for offenders who commit serious violent offences including sexual offences and domestic violence. A new community programme commenced in January 2006 to address serious violent offending, for example, at the PBNI Integrated Supervision Unit, Alderwood House, Belfast, probation staff deliver sex offender treatment programmes, domestic violence programmes and other programmes, again with limited input from mental health and learning disability services.

7.8 There are currently 4 probation hostels in Northern Ireland that allocate beds to bailees. McCall (2005)[1] found that unmet need had been identified in theWestern Health and Social Services Board where there were 12 beds in a community supervised hostel, but it was considered that a minimum of 24 beds was required to meet the current needs. There are significant and well established working partnerships with voluntary agencies in Northern Ireland. These services provide accommodation, vocational training, skill development and employment opportunities for offenders with mental health problems, learning disabilities and personality disorders.

7.9 McCall (2005)[1] found little information about mentally disordered offenders on probation. The main findings were:

- male probationers had higher death rates and suicide rates than the general population (1 cohort study);
- the majority of referrals from a probation hostel to a forensic psychiatry department were for complaints of depression and concerns regarding self-harm; and
- the quality of probation officer-probationer relationships can colour the use of strategies to monitor and enforce treatment compliance. A respectful, personal approach was perceived as being more effective than those that were more authoritarian.

STANDARDS

Standard 1. A Co-Ordinated Joint Strategic Approach

7.10 Current experience indicates that many service users in contact with probation welcome a joint and co-ordinated approach between probation and mental health and learning disability services that addresses both the mental and the criminal justice needs of the individual and his or her carers. In order to effectively carry out their functions probation staff should be aware of the presence and nature of any mental health needs that are relevant to:

- the risks of harm the individual poses to him or herself or to others, including the risks of reoffending; and
- the monitoring, supervision and rehabilitation of the individual.

7.11 Probation staff require access to timely assessment, advice, treatment and care provided by mental health and learning disability services. These services are required when individuals are undergoing assessment for the courts or for the Life Sentence Review Commission or when individuals are subject to Probation Orders and Custody Probation Orders. The sources of assessment and advice must be independent – psychological or psychiatric assessments commissioned by the defence may be given a limited and incomplete remit, for example they may not adequately address issues of risk.

7.12 Mental health and learning disability services may also benefit from information from probation services, for example, to help understand the legal circumstances of service users. There are opportunities for service providers to jointly address identified problems.

7.13 At present mental health and learning disability services are neither configured nor resourced to provide the services that are envisaged and there are a number of perceived or actual obstacles to joint approaches. Joint strategies must address these issues.

Recommendations

68. Strategies should be developed to ensure effective joint working between PBNI and the full range of mental health and learning disability services in relation to the assessment, treatment and care of mentally disordered people who are undergoing assessment by Probation or are subject to a Probation Order.

69. The Regional Forensic Network should co-ordinate the development of services at the interfaces between PBNI and:

    - community forensic mental health and learning disability services;
    - prison forensic services; and
    - inpatient secure services.

70. The DHSSPS should, in partnership with PBNI, co-ordinate the development of services at the interfaces between PBNI and other mental health services.

Standard 2. Evidence, Principles and Purposes

7.14 There is a need for more detailed information on the mental health needs of service users and carers in contact with probation services and the Review recommends that detailed needs assessments should be commissioned. However, the current service needs are so substantial that the results of a full needs assessment are not required before service development can begin.

7.15 The joint services should have clearly defined purposes, should contribute to evidence gathering and should be consistent with the values and principles advocated by the Review These services should assess the needs of each individual, his or her carers, their representatives, service providers and the wider community. The services should not only seek to identify, assess and provide treatment and care for those with mental health problems, but they should also target those causing greatest concern, developing particular expertise in relation to the assessment and management of problems and needs related to personality disorder.

Recommendation

71. PBNI, the Regional Forensic Network and the DHSSPS should agree joint arrangements to assess and monitor the needs of mentally disordered individuals, their carers, their representatives, service providers and the wider community. The results of ongoing assessment should inform service planning.

Standard 3. Organisational Structures and Interconnections

7.16 In these joint services staff should work flexibly in partnership with each other and in support of interconnecting health and social services providers and with criminal justice agencies in the statutory, voluntary and community sectors. The services should develop models of good practice, including clear organisational structures and lines of accountability and also policies, protocols and procedures for joint working and information sharing.

Recommendation

72. PBNI, the Regional Forensic Network and the DHSSPS should agree joint purposes, clear organisational structures and lines of accountability and should develop policies, protocols and procedures for joint working and information sharing.

Standard 4. Comprehensive and Accessible Services

7.17 Comprehensive services should be developed jointly by PBNI and forensic and other mental health and learning disability services to provide timely, accessible and high quality assessment of needs, treatment and care for service users and support for their carers with continuity of services for as long as required. Arrangements for joint working must address the full range of biological, psychological and social needs and in particular services should be developed in a manner that promotes openness and good communication between all relevant people, while respecting the rights of the individual for privacy and confidentiality.

Recommendation

73. PBNI, the Regional Forensic Network and the DHSSPS should develop comprehensive and accessible joint services to assess and provide treatment and care for mentally disordered people in contact with probation. There are particular needs to develop joint psychotherapeutic approaches.

Standard 5. Risk Assessment and Management

7.18 The pilot services should contribute to the assessment and management of risk, including the development of joint policies, protocols and procedures.

Recommendation

74. The DHSSPS in partnership with Criminal Justice Agencies should establish a group comprising relevant stakeholders to develop a risk assessment and management framework that extends across the Criminal Justice System and the HPSS and that applies to mentally disordered people undergoing assessment by Probation or subject to a Probation Order.

Standard 6. Quality Assurance

Recommendation

75. PBNI, the Regional Forensic Network and the DHSSPS should agree standards for joint working. Services should be subject to internal and external evaluation of performance and quality.

Standard 7. Mental Health Promotion and Education

7.20 There are substantial opportunities to promote the mental health of those in contact with probation. The joint services should examine the services that may be developed and the potential benefits, including promoting continuity of mental health promotion when individuals are discharged from prison to the community.

Recommendation

76. PBNI and mental health and learning disability services should identify opportunities for mental health promotion and agree appropriate services.

Standard 8. Information, Research and Innovation

7.21 The needs assessment and joint services should add to the available information and should indicate future directions for research. Services should explore the possible uses of information technology including possible interfaces between mental health information systems and criminal justice information systems such as Causeway.

Standard 9. Recruitment, Retention and Developing a Skilled Workforce

7.22 There are needs to ensure that mental health and learning disability staff become familiar with the work of probation and that probation staff develop their capacities in recognising and responding to mental health needs. Following assessment of needs, inter-agency learning and development should be established for professionals working with offenders with mental illness, learning disability, personality disorder and alcohol and substance misuse.

7.23 Workforce planning is essential to ensure that developments in Forensic Services are supported by the recruitment and retention of appropriate numbers of staff.

Recommendation

77. Inter-agency learning and development arrangements should be established to support joint working between PBNI and forensic and other mental health and learning disability services.

Standard 10. Sustainable and Transparent Funding

7.24 **Recommendation**

78. The development of forensic and other mental health and learning disability services to support the work of PBNI requires sustainable funding from the relevant sources. Funding arrangements must support the joint co-ordinated planning and delivery of services. There should be mechanisms to demonstrate that monies made available to services have reached their intended targets.

CHAPTER 8

SECURE INPATIENT SERVICES

INTRODUCTION

8.1 Inpatient services are essential components in the range of Forensic Services. Service users should have timely access to safe inpatient environments that provide treatment and care to meet the needs of each individual thus maximising his or her prospects of experiencing improvement in mental health and a safe return to the community.

8.2 Inpatient forensic services are stratified according to the risk the service users present[27]. Security is considered according to environmental, relational and procedural aspects and is often described as comprising high, medium and low levels of security.

These levels of security have been described as follows[28]:

*"**High Security** is the level of security necessary only for those patients who pose a grave and immediate danger to others if at large. Security arrangements should be capable of preventing even the most determined absconder. High secure services should only be provided in secure hospitals with a full range of therapeutic and recreational facilities within the perimeter fence, acknowledging the severe limitations on the use of outside services and facilities.*

***Medium Security** is the level of security necessary for patients who represent a serious but less immediate danger to others. Patients will often have been dealt with in the Crown Courts and present a serious risk to others combined with the potential to abscond. Security should therefore be sufficient to deter all but the most determined. A good range of therapeutic and recreational facilities should be available within the perimeter fence to meet the needs of patients who are not ready for off-site parole, but with the emphasis on graduated use of ordinary community facilities in rehabilitation whenever possible.*

***Low Security** is the level of security deemed necessary for patients who present a less serious physical danger to others, often dealt with in the Magistrates Courts and identified by court assessment/diversion schemes. Security measures are intended to impede rather than completely prevent absconsions, with greater reliance on staffing arrangements and less reliance on physical security measures."*

8.3 Inpatient services can be further subdivided according to length of stay, for example into the following classification (adapted from Kennedy 2002[27]):

- High security;
- Medium term medium security;
- Long term medium security;
- Acute/medium term low security; and
- Long term low security.

8.4 Although these descriptions help give some understanding of the different levels of security there is a need to develop more objective criteria based on the characteristics of service users and their needs.

8.5 Work has progressed to set standards for the care of service users in secure facilitiesx [29]. It is essential that services are person-centred, of high quality and that they have internal quality assurance mechanisms and independent external scrutiny.

8.6 All the services at different levels of security must work in concert with each other and with interconnecting forensic and other mental health and learning disability services. It is essential that services have the capacity to admit each service user in a timely manner to a facility that meets his or her needs and that service users are not subject to any greater restriction than their condition or legal status requires.

8.7 It has been demonstrated that well developed adult mental health services, including low secure services, correlate with reduced demand for services at higher levels of security[30]. Secure places inevitably entail restriction of the liberty of service users as well as significant financial costs for society. The Review believes that secure inpatient services are necessary and that places must be made available to all who require them. Investment in interconnecting and step-down mental health and learning disability services is required to help keep the total number of such secure places at a minimum.

8.8 This chapter considers primarily the secure inpatient needs of adults with mental illness. The needs of those with learning disability are considered in Chapter 10, those with personality disorder in Chapter 11 and the needs of children and adolescents are considered in the report by the Child and Adolescent Mental Health Committee[86].

HIGH SECURE SERVICES

Introduction

8.9 There is no high secure hospital in Northern Ireland. The State Hospital, Carstairs, Scotland, has provided most of the care and treatment in conditions of high security for adults from Northern Ireland with mental illness or severe mental impairment who, because of their dangerous, violent or criminal propensities, cannot be cared for in any other setting.

8.10 Service users have been transferred to the State Hospital from hospitals in Northern Ireland and some of these service users have originated from the courts and prisons. Once it is agreed that a service user has made sufficient progress at the State Hospital he or she generally returns to the referring hospital in Northern Ireland. Until Shannon Clinic, Northern Ireland's Regional Medium Secure Unit, was opened in April 2005 there was a gap between the high security provision at the State Hospital and the low security of the Psychiatric Intensive Care and other units in Northern Ireland. This meant that patients in the State Hospital needed to have made sufficient improvement to be returned to a low security environment before they were likely to be accepted back to Northern Ireland. It will be essential that any service users who have been transferred to facilities outside Northern Ireland are returned at the earliest appropriate opportunity. Current capacity must be further developed to meet this objective.

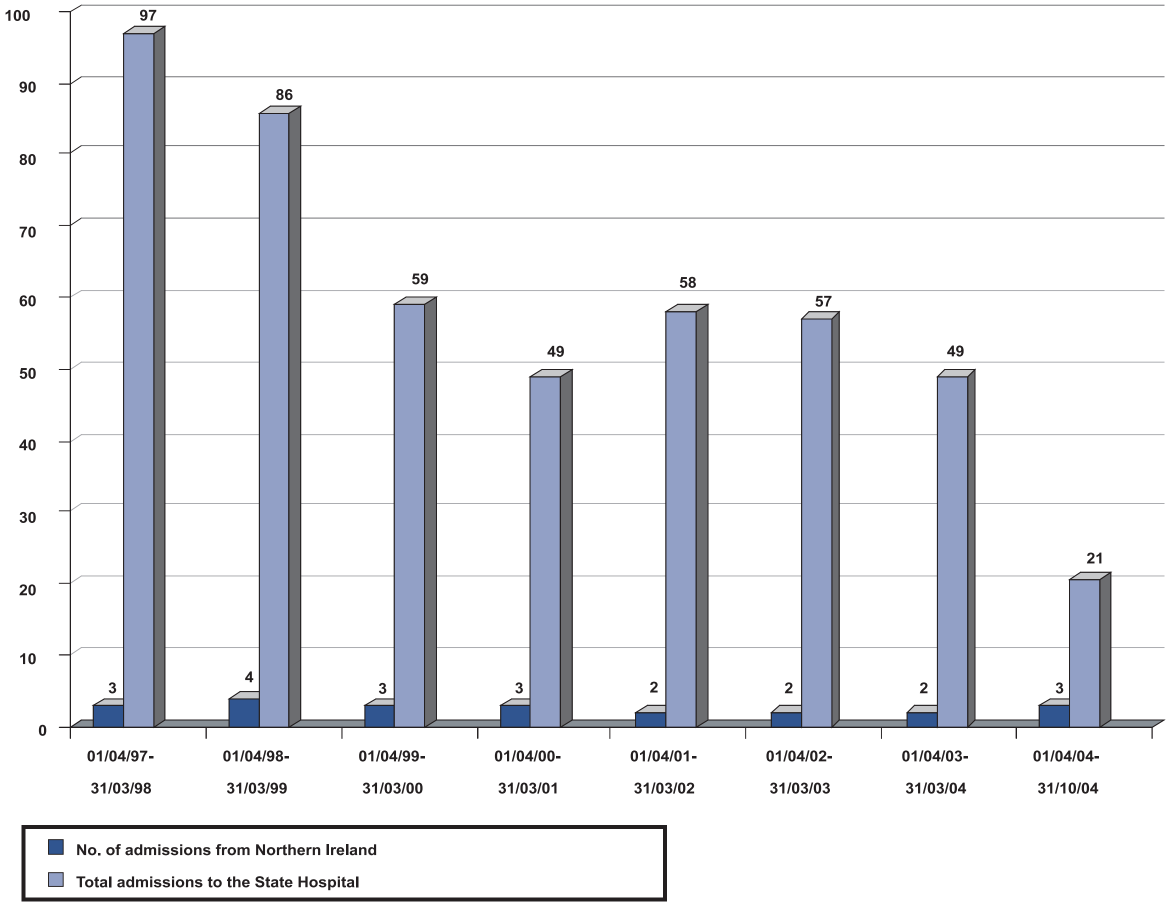
BACKGROUND

8.11 McCall (2005)[1] has reviewed the literature in relation to high secure services. Badger (1999)[31] found that there were about 33 patients in special hospitals per million of the population in Britain, with 4 times as many men as women. The average age was in the 30's but with a wide age range. About two thirds of patients were legally classified as mentally ill and a one quarter had a personality disorder The average length of stay was 8 years with rather longer periods of stay for women. About two thirds of patients had an index offence of violence against the person, with about a quarter of all patients having committed homicide. Substantial ethnic differences have been observed among admissions [32]. It has been estimated that at least half of the patients in special hospitals do not require the highest level of security. The average length of stay at the State Hospital between 1992-1997 was 5 years with a readmission rate of 22.3%, mostly due to violence[33].

CURRENT NEEDS AND SERVICES

8.12 The State Hospital provides care and treatment for around 240 patients from Scotland and Northern Ireland.

Admissions from Northern Ireland to the State Hospital, 2004



8.13 The State Hospital rarely admits patients with a primary diagnosis of personality disorder[34].

8.14 The number of mentally ill patients in the State Hospital who originated from Northern Ireland reduced substantially following the opening of the Shannon Clinic Regional Secure Unit in April 2005.

8.15 Northern Ireland has traditionally admitted fewer patients to high secure care than Scotland and England despite a lower resource base. These low numbers of admissions to the State Hospital from Northern Ireland may be an indicator that need is not being adequately met.

8.16 There are substantial obstacles to admission to the State Hospital for service users from Northern Ireland. Currently people who are remanded to prison and who are suffering from mental disorder that warrants transfer to a high secure service cannot be remanded to a hospital outside the Northern Ireland jurisdiction and thus cannot receive appropriate treatment in conditions of high security until their case has been dealt with by the courts. The provision of psychiatric treatment in prison is strictly limited, for example, a prisoner who is so mentally ill that he or she does not appreciate the need for treatment cannot be given treatment in prison under the protection of mental health legislation. Such a prisoner may have to remain on remand in prison for a prolonged period, perhaps a year or more, without receiving adequate treatment. Similarly individuals whose circumstances may warrant an interim hospital order to the State Hospital cannot be transferred outside of the Northern Ireland jurisdiction. Section 81 of the Mental Health (Scotland) Act 1984[35] (as amended by The Mental Health (Northern Ireland) (Consequential Amendments) Order 1986[36] specifically excludes people subject to remand for assessment or treatment or to an interim hospital order (Articles 42, 43 and 45 of the Mental Health (Northern Ireland) Order 1986) from the arrangements for removal to Scotland of patients in Northern Ireland. It is a highly unsatisfactory situation that service users from Northern Ireland are unable to have access to treatment and care in conditions of high security when their condition requires it.

8.17 Obstacles have also arisen to the return to Northern Ireland of service users whose diagnosis has changed while undergoing assessment and treatment in Scotland. Uncertainty has arisen in relation to the meaning of the term “severe mental handicap” in the Mental Health (Northern Ireland) Order 1986[11]. These issues are discussed further in Chapter 10 and in the report on Legal Issues by this Review.

APPEALS AGAINST LEVELS OF SECURITY

8.18 Provisions are included in the Mental Health (Care and Treatment) (Scotland) Act 2003[37] to allow for appeal against detention in conditions of excessive security. Service users from Northern Ireland who are detained inappropriately in conditions of excessive security at the State Hospital will be able to avail of the provisions in the Scottish legislation when they come into effect in May 2006. This is likely to result in pressure to admit to Shannon Clinic service users whose requirements are for longer term medium security rather than the medium term treatment, for which the Shannon Clinic was originally planned. If such service users are admitted to Shannon Clinic, the capacity of the clinic to respond to service users who need short and medium term care will be reduced.

WOMEN IN HIGH SECURE SERVICES

8.19 Historically very low numbers of women service users from Northern Ireland have required treatment in conditions of high security. At the time of writing this Report there are no women service users from Northern Ireland in the State Hospital. A report for the Forensic Mental Health Services Managed Care Network in Scotland [38] has recommended that dedicated multi-disciplinary teams responsible for providing forensic psychiatry services for women should be established within local forensic services across Scotland. It also recommended that until Secure Services for Women are available Scotland-wide, the Women's Service at the State Hospital should continue and that only once there is clearly no need for the service should it be closed.

NEEDS OF USERS AND CARERS

8.20 The State Hospital has introduced a number of measures to improve the experiences of service users and carers such as improvements in information and communication, the implementation of Integrated Care Pathways, the provision of a Patients' Advocacy Service and the formation of a Patient Partnership Forum and a Carers' Reference Group[39].

STAKEHOLDER VIEWS AND USER/CARER VIEWS

8.21 McCall (2005)[1] found mixed views in relation to the service provided by the State Hospital for service users and carers in Northern Ireland. There were concerns about the geographical distance and separation from families and also, about the secure environment, but there was also appreciation of the treatments and facilities available there.

STANDARDS

Standard 1. A Co-Ordinated Joint Strategic Approach

8.22 At present, in the absence of more suitable alternative provision, service users in Northern Ireland continue to require high secure services from the State Hospital in Carstairs. While these arrangements continue Forensic Services in Northern Ireland should co-ordinate with Forensic Services in Scotland, both in relation to the provision of effective clinical services and also in relation to sharing and developing best practice. This co-ordination should occur through various mechanisms such as regular liaison between the Northern Ireland Forensic Managed Network and the Scottish Forensic Mental Health Services Managed Care Network and between Shannon Clinic and the State Hospital. Arrangements should be put in place to ensure that co-ordination occurs between all relevant parties, including multi-disciplinary staff and user and carer advocates.

Recommendation

79. The Regional Forensic Network should promote co-ordination of forensic service provision for the people of Northern Ireland, including with high security services at the State Hospital, Carstairs, Scotland.

Standard 2. Evidence, Principles and Purposes

8.23 The principles of this Review require that all service users have ready access to high quality care. It is, therefore, essential that all service users have access to assessment, treatment and care in conditions of high security if their condition requires it. However, certain service users are denied this option, namely prisoners on remand and people who may benefit from assessment and treatment in a high secure service while the subject of an interim hospital order. There are substantially fewer admissions to high secure services from Northern Ireland than from other jurisdictions in the United Kingdom. Certain service users in Northern Ireland remain inappropriately placed in prison when they should be in hospital. The Review considers that the current arrangements are highly unsatisfactory. It strongly urges that a solution is found urgently and as a matter of priority.

8.24 The Review has discussed a number of ways in which this situation might be resolved. These options include:

(i) arrangements to "fast-track" the legal cases of mentally disordered people;

(ii) changes in the legislation to enable people whose condition requires treatment in high security to receive such treatment either in Scotland or elsewhere;

(iii) changing the use of the Shannon Clinic Regional Secure Unit so that in some circumstances it provides treatment and care in conditions equivalent to high security; and

(iv) building a high secure hospital in Northern Ireland.

8.25 Option 1 the "fast-tracking" of legal cases would require agreements with the Public Prosecution Service and the Court Services to process more speedily cases where it appears that the accused is suffering from mental disorder and cannot be provided with appropriate treatment while in prison. Such arrangements may help shorten the period an individual may spend in prison on remand or awaiting sentencing, but these periods are still likely to remain unacceptably long. Such arrangements could not offer the individual the benefit of being assessed and treated in hospital before disposal by the courts. Therefore, this option is unlikely to present a complete or satisfactory solution to the identified problem.

8.26 Option 2 involves changes in primary legislation to facilitate transfers to high secure services in Scotland or other jurisdictions. There are likely to be substantial legal and practical difficulties in transferring service users outside of the jurisdiction while they are still subject to the Northern Ireland courts. It should also be noted that there are high secure services in England and in the Republic of Ireland. The current mental health legislation allows for transfer of service users between Northern Ireland and other parts of the United Kingdom, but there is currently no reciprocal mental health legislation that allows transfers between Northern Ireland and the Republic of Ireland. There are substantial potential opportunities for the development of forensic services on an all-Ireland basis.

8.27 Option 3 was considered by the DHSS/NIO review of secure provision (1994)[30]. It debated whether Northern Ireland should manage all its patients, including those requiring high security facilities, but it decided that the services at the State Hospital would continue to be required. It suggested the Regional Secure Unit could have its security level upgraded at a later stage. However, the building was specified and designed as a medium secure unit and is likely to require very substantial modification to upgrade it to high secure levels, if indeed that is feasible. The Regional Secure Unit was also specified at a level of 20 beds per million of the population, which is lower than the levels subsequently recommended elsewhere. The lack of provision for service users requiring long stay medium security and the lack of 'step-down' facilities from Shannon Clinic are likely to create a very high demand for the places in the Clinic. Converting part of the unit to high secure usage would compromise the capacity of the Unit to provide the medium secure service that was originally intended.

8.28 Option 4 involves building an additional secure facility in Northern Ireland to accommodate service users who require treatment and care in conditions of high security. On the face of it this option may not seem feasible on account of the small numbers of service users from Northern Ireland who are currently in high security. However, it should be noted that the numbers of service users from Northern Ireland who are receiving treatment in conditions of high security are substantially lower than in other jurisdictions. Current usage of high secure services does not reflect actual need because the legal and other obstacles prevent service users gaining access to the high security conditions they require.

8.29 At present there are a number of major gaps in high and medium secure provision for service users in Northern Ireland:

- unsentenced prisoners sufering from mental illness or severe mental impairment are denied the treatment they require as they cannot be transferred to a high security service;
- there is no provision for long stay medium secure places leading to inefficient usage of resources at Shannon Clinic;
- facilities for women at Shannon Clinic are limited. Women would benefit from a separate facility and the places at Shannon Clinic could be used by men;
- there is a need to provide treatment in conditions of high security for individuals suffering from personality disorder (see Chapter 11); and
- there are no secure facilities for adolescents.

8.30 An additional secure facility could provide a comprehensive solution to the high and medium secure needs of service users from Northern Ireland. Consideration should be given to providing these specialist services within an all-Ireland framework.

Recommendations

80. The current arrangements for high secure services for people in Northern Ireland have unacceptable gaps in service provision. All people in Northern Ireland must have access to high secure services when they require them. The DHSSPS must take the lead in urgently finding solutions to the current obstacles to treatment and care in conditions of high security.

81. The DHSSPS must commission an assessment of needs to determine the numbers of people from Northern Ireland who require treatment in conditions of high and medium security. The assessment should include people suffering from mental illness, severe mental impairment and from personality disorder. It should encompass those who are currently receiving services and those who are currently unable for legal or other reasons to avail of such assessment, treatment and care.

82. This assessment of high and medium secure needs should be combined with an assessment of the needs for low secure and step-down community services (Chapter 9) and the needs for forensic learning disability services (Chapter 10).

83. The Review recommends the provision of an additional secure facility in Northern Ireland to meet the identified high and medium secure needs of service users. The regional high and medium secure facilities should be complemented by local low secure facilities and community step-down facilities to form a range of short, medium and longer stay facilities that meet the needs of forensic service users.

Standards 3-9

8.31 In developing new secure services consideration should be given to each aspect of the care standards proposed in Chapter 2 including the development of policies, procedures and protocols, risk assessment and management, quality standards and assurance mechanisms, the development of information systems, joint research and contributions to mental health promotion and public education. There are also many opportunities for sharing of good practice, for example, in relation to advocacy and clinical services, and there are opportunities for innovation such as the use of video-links to improve contact between carers and service users. In addition, consideration should also be given to developing joint training between Northern Ireland Forensic Services and those available in adjacent jurisdictions.

Recommendations

84. New secure services should be developed in accordance with the standards proposed by this Review.

85. The Regional Forensic Network should explore the range of opportunities to co-ordinate training for staff in Forensic Mental Health and Learning Disability Services in Northern Ireland with the training available in adjacent jurisdictions.

MEDIUM SECURE SERVICES

Introduction and Current Services

8.32 The Shannon Clinic Regional Secure Unit (the Clinic) at Knockbracken Healthcare Park, Belfast, was opened in April 2005. When fully operational it will provide 34 medium secure places for the assessment and treatment of adults suffering from mental illness. Shannon Clinic takes admissions from prisons, courts, high secure services and other mental health services. Admissions generally warrant detention under the Mental Health (Northern Ireland) Order 1986[11] and comprise individuals who are a serious and enduring risk to others and prisoners who are mentally ill and require treatment in a medium secure setting. The Clinic primarily takes admissions ranging from several weeks to approximately 2 years. There is currently no provision in Northern Ireland for service users requiring longer stay treatment in conditions of medium security.

8.33 Facilities are available in Shannon Clinic for a small number of women to reside in part of a ward area that is separate from the facilities for men, but with access to shared activities and rehabilitation facilities.

8.34 The Clinic has an established a model of care that guides its activities and operations:

- A Bio-Psycho-Social Model;
- Patient Centred Approach;
- Multi-disciplinary Team Approach;
- Supports Patient Recovery;
- Safe, Secure and Therapeutic Environment;
- Promotes a Learning Ethos for Staff and Patients; and
- Involving Patients and Families in the Care Planning Process.

8.35 Service users and carers are also supported by user and carer advocates.

8.36 The Clinic has formulated many policies, procedures and protocols and is developing integrated care pathways, needs assessment, care planning, risk assessment and management procedures, standards, audit and quality assurance systems. The Clinic is also using computerised notes and records and video-links.

8.37 The Clinic has developed networks with interconnecting services and has also established an extensive staff training programme.

8.38 This chapter considers the future development of medium secure services for mentally ill adults in Northern Ireland.

DISCUSSION AND RECOMMENDATIONS

Standard 1. A Co-Ordinated Joint Strategic Approach

8.39 The development of the Clinic has been overseen by a regional project board. It is expected that the function of regional co-ordination will be adopted by a Regional Forensic Network which will have links to the Scottish Forensic Mental Health Services Managed Care Network.

Recommendation

86. The Regional Forensic Network should promote the development and delivery of regional medium secure services and their co-ordination with interconnecting services.

Standard 2. Evidence, Principles and Purposes

8.40 The Clinic has been commissioned as a short and medium term facility for adults with mental illness, providing assessment and medium term treatment for periods of up to 2 years. The capacity of the Clinic to effectively provide this service will depend heavily on the provision of interconnecting services throughout Northern Ireland to act in concert with the Clinic by providing long term medium secure services and step down low secure and community forensic services. Unless these facilities are made available there is a very real danger that service users will spend longer in the Clinic than is clinically necessary and that the Clinic will not be able to offer places to those in urgent need such as mentally ill people in prison. Such an outcome would also represent an inefficient use of the taxpayers' investment in this facility.

8.41 Kennedy[27] has stated that "Patients who are failing to progress despite appropriate trials of treatment need not continue to occupy scarce intensive therapeutic placements." He has suggested that such individuals may become frustrated by their lack of progress and that after detailed review of treatments and needs these individuals should be allocated to a long term placements where they are kept under regular review and may from time to time benefit from a return to a more intensive treatment setting.

8.42 It is essential that a detailed assessment of need is carried out and that adequate long term medium secure, low secure and community services are provided to support the efficient functioning of the Clinic.

8.43 In addition to the detailed needs assessment exercise the Clinic should contribute to the understanding of the needs for service provision by analysing both the needs of each service user and also the constraints on their progress. The Clinic should explore the development of a standardised Analysis of Constraints methodology[41] to identify the obstacles that are blocking the progress of each service user towards reduced restriction and greater autonomy. Identified constraints might include, for example, specific features of the service user's mental condition and lack of services to meet the identified needs.

8.44 The Regional Forensic Network should establish systems to monitor ongoing need for forensic services, including places in conditions of medium security. This information should inform planning for high, medium and low secure services and step-down community services for service users with short, medium and longer stay needs. The aim must be to create detailed information systems that inform the planning and delivery of an interconnected range of secure inpatient and community services to meet the needs of service users.

Recommendations

87. The DHSSPS must take account of the assessment of need for secure services and it must plan and develop long stay medium secure services and step-down low secure and community services.

88. In order to inform service planning and development Shannon Clinic staff should analyse the needs of each service user and the constraints on his or her progress.

89. The Regional Forensic Network should establish systems to monitor ongoing need for high, medium and low secure services and step-down community services for forensic service users with short, medium and longer stay needs. This information should contribute to the planning and delivery of forensic services.

Standard 3. Organisational Structures and Interconnections

8.45 The service based at the Clinic is closely connected to community forensic services which are at an early stage of development. Staff work across organisational boundaries to promote co-ordination. The Clinic has also been working in close collaboration with the State Hospital. It is essential that similar close connections are established between the Clinic and the prisons. These should be agreed at an early stage to ensure that robust systems are put in place to identify and transfer mentally ill prisoners in need of assessment and treatment in conditions of medium security. Previous experience in the Northern Ireland prisons demonstrated the benefits of staff working jointly between an inpatient hospital unit and the prison healthcare centre – greater numbers of transfers to hospital occurred and in shorter periods of time, compared with other parts of the province that did not operate such an arrangement.

Recommendation

90. Commissioners of mental health and learning disability services to the prisons should ensure that arrangements facilitate the early identification and transfer to hospital of mentally disordered people who require treatment in conditions of medium security.

Standard 4. Comprehensive and Accessible Services

8.46 Comprehensive arrangements have been made at the Clinic to assess and meet the needs of service users and carers. Partnerships have been developed with many relevant parties and joint protocols are being produced in partnership with Criminal Justice Agencies. A range of psychotherapeutic approaches is being developed including group and individual therapy and staff supervision and support.

Standard 5. Risk Assessment and Management

8.47 Each mental health and learning disability service must develop risk assessment and management systems that are generically similar and that are tailored to the needs and circumstances of the individual service user. The Clinic is developing expertise, policies, procedures and protocols. These should draw upon best practice.

Recommendation

91. Service providers should develop regional expertise at Shannon Clinic in the assessment and management of risk in relation to service users who require assessment, treatment and care in conditions of medium security.

Standard 6. Quality Assurance

8.48 The Clinic is introducing systems to assess performance and assure quality and clinical governance.

8.49 One of the criteria used to assess the efficacy of the Clinic should be its capacity to take service users at short notice, including mentally ill prisoners in need of assessment and treatment in conditions of medium security . This criterion is not under the control of the Clinic service alone – it will depend heavily on the ability of interconnecting services throughout Northern Ireland to act in concert with the Clinic by providing long term, step-down and community forensic services.

Recommendation

92. Shannon Clinic should develop explicit quality standards and quality assurance mechanisms, including audit and independent external inspection by the relevant regional body.

Standard 7. Mental Health Promotion and Education

8.50 The Clinic is developing arrangements to promote the physical and mental health of service users and has also contributed to public education.

Recommendation

93. The Regional Forensic Network should co-ordinate with the regional body with responsibility for mental health promotion to facilitate the contribution of secure inpatient services to mental health promotion and public education.

Standard 8. Information, Research and Innovation

8.51 The Clinic has sought to develop an ethos of enquiry that promotes information-gathering and research and this ethos is supported by internal organisational structures. It will be important to develop a research strategy that includes links with relevant research bodies.

8.52 Information Technology systems have been introduced to the Clinic and are undergoing further development as part of a wider project.

Recommendations

94. The Regional Forensic Network should develop information and research strategies and promote the involvement of secure inpatient services.

95. The Regional Forensic Network should promote the integration of InformationTechnology systems between medium secure services and interconnecting services to help ensure the effective transfer of information.

Standard 9. Recruitment, Retention and Developing a Skilled Workforce

8.53 The Clinic has developed an extensive learning and development programme that is closely related to clinical practice. This should be developed further by increasing links with universities and other training organisations and by working with other developing forensic services and the Regional Forensic Network.

8.54 Staff working with mentally disordered offenders also require psychotherapeutic support and arrangements have been made to provide psychotherapy services.

8.55 At the time of writing this Report, shortages of key trained staff have prevented the Clinic from opening to full capacity and they have impeded the development of community forensic services. These obstacles demonstrate the crucial importance of developing workforce strategies to ensure the recruitment, training and retention of all the necessary staff to support service developments.

Recommendations

96. The model used by Shannon Clinic of closely integrating training with clinical practice should extended to other forensic services.

97. The DHSSPS must ensure that development and maintenance of secure inpatient services is supported by robust workforce planning and provision of opportunities for staff to avail of learning, development and support.

Standard 10. Sustainable and Transparent Funding

8.56 The further development of medium secure services to meet the needs of service users for short, medium and long stay treatment and care will require appropriate funding in accordance with a long term plan.

Recommendation

98. The development and maintenance of medium secure services requires appropriate funding in accordance with a long term plan that ensures sustainable development of services. There must be mechanisms that demonstrate that monies made available to services have reached their intended targets.

LOW SECURE SERVICES

Introduction

8.57 Low secure services include Psychiatric Intensive Care Units, challenging behaviour wards and acute and longer term forensic low secure units.

8.58 The DHSS/NIO Review of Secure Provision[40] noted there were then 150 locked ward (low secure) beds in Northern Ireland. The Review recommended building a Medium Secure Unit for the province and rationalising locked ward provision.

8.59 The Northern Ireland Hospital Advisory Service inspected the 6 Psychiatric Intensive Care Units in the mid 1990's. It found substantially different practices in these units.

8.60 The Report of the Adult Mental Health Services Committee[83] (Chapter 4.125) has recommended, as part of a comprehensive package of services, that there should be 25 challenging behaviour beds per 250,000 of the population, which equates to a total of 170 for the province.

8.61 Low secure services are essential to support users in community and inpatient adult mental health services, to provide step-down facilities for service users in medium and high security and to provide support to users of community forensic services. Low secure services must function in a co-ordinated manner with all other interconnected services in order to meet the needs of service users. Inadequate capacity in low secure services may have a number of knock-on effects on interconnected services, for example, if a low secure place is unavailable to a service user in medium security he or she may be forced to spend a longer period than necessary at that higher level of security and may render that place unavailable for other service users in urgent need.

BACKGROUND

Current Services

8.62 The table below shows current provision of low secure beds in Northern Ireland. There are 6 Psychiatric Intensive Care Units (PICUs) which have provided a number of different functions including the short, medium and longer term treatment of mentally ill adults. In some cases these units have provided care for some mentally ill adolescents and accepted transfers from prisons and high secure services.

8.63 There are also challenging behaviour wards which typically provide for longer stay patients and where the emphasis is on rehabilitation.

Current provision of low secure beds in Northern Ireland

Hospital	Number of PICU beds	Number of long stay on locked/lockable wards	Total beds on locked/lockable wards
Knockbracken	16	24	40
Downshire	16	0	16
Holywell	18	22	40
Tyrone and Fermanagh	10	0	10
Gransha	8	0	8
St Lukes	13	17	30
Total	81	63	144

8.64 There are substantial variations in provision between different geographical areas. Many wards are in old buildings and offer dormitory accommodation and limited facilities and activities.

Literature Review

8.65 McCall (2005)[1] has reviewed the limited literature on the efficacy of low secure units and the epidemiological features of patients in low secure care. The main findings were as follows:

- wide variation in the provision and nature of low secure care reflecting idiosyncratic and localised development of services;
- almost complete lack of research evidence on the efficacy of low secure care for particular types of patients and problems;
- offenders were significantly less likely to be aggressive to others than non-offenders, but significantly more likely to self-harm, however, treatment outcomes were similar for both groups (results of 1 study[42]); and
- enhanced availability of local low secure reduces demand for medium and high secure services[30].

DISCUSSION AND RECOMMENDATIONS

Standard 1. A Co-Ordinated Joint Strategic Approach

8.66 Low secure services are essential components of adult mental health and forensic services and must work in co-ordination with interconnecting services. It is essential that future services are planned jointly by all relevant parties.

Recommendation

99. The DHSSPS should ensure the development and delivery of low secure forensic services including step-down rehabilitation and long-stay services.

Standard 2. Evidence, Principles and Purposes

8.67 There is a lack of detailed information on the needs of service users in Northern Ireland for low secure accommodation. There is a requirement for a needs assessment and service mapping exercise. This should consider the needs of service users who are currently in low secure accommodation and those who may require low secure accommodation, for example, some service users in high and medium security, in prison, in acute admission wards, in longer stay wards and in the community. The exercise should take account of different admission criteria to current low secure services. Having identified the detailed needs of service users, options for services should be considered that will ensure adequate capacity to meet current and projected future needs. The appropriate occupancy rates should be calculated that will meet needs and ensure availability of places when required. The assessment of needs for low secure places should be integrated with assessment of need for medium and high secure places. Low secure services will also require linkages to accommodation and services in the community to ensure these are available once service users are ready to move there.

8.68 Options for the future development of low secure services should consider the quality of the services that are required, including the standard of physical accommodation and the levels of therapy and care. If service users spend significant periods in locked or restricted accommodation there is a clear need to provide a wide range of facilities such as therapeutic, occupational, recreational and outdoor activities. Other factors to be considered include:

- the number of categories of low secure services;
- the specific needs of certain groups such as women; and
- the key linkages of services, for example, PICU's may be more closely linked to admission units and low secure forensic units may be more closely linked to forensic services. It is generally inappropriate to place in PICU's individuals who require rehabilitation in a secure and low stimulus environment.

8.69 Different arrangements may be developed in different localities, but the essential features are that services should be developed in partnership with all the relevant parties and they should provide the number of places and quality of services required to allow service users to be placed in good quality accommodation and according to their needs rather than according to the availability or otherwise of a place. Substantial new provision of low secure inpatient facilities is likely to be required to meet current and projected needs.

Recommendations

100. The DHSSPS must commission an assessment of needs to determine the numbers of people from Northern Ireland who require treatment in conditions of low security The assessment should include people suffering from mental illness, severe mental impairment and from personality disorder. It should encompass those who are currently receiving services and those who are currently unable for legal or other reasons to avail of such assessment, treatment and care.

101. The needs assessment should consider the optimal configuration of low secure services, including the needs of specific groups such as women.

102. The needs assessment should lead to the development of low secure services that are fit for purpose. This is likely to require substantial new provision.

Standards 3-10.

8.70 Future low secure services should be developed following assessment of need and in accordance with the principles advocated in this report.

Recommendation

103. It is recommended that future low secure services, including low secure forensic services are developed in accordance with the standards advocated in Chapter 2.

CHAPTER 9

COMMUNITY FORENSIC SERVICES

INTRODUCTION

9.1 Community Forensic Services are an essential component of co-ordinated regional forensic services. They provide a range of community resources for service users and carers, the Criminal Justice System and for other mental health and learning disability services.

9.2 The sources of referral may include:

- inpatient forensic services;
- other inpatient and community mental health and learning disability services;
- police stations and courts;
- prison services; and
- probation services.

9.3 Community forensic services have crucial roles in meeting the needs of service users and carers, for example, in supporting the timely discharge of service users from secure inpatient services to appropriate accommodation in the community, in providing follow-up treatment and care for mentally disordered people discharged from prison or in providing assessment and therapeutic support to probation or to other mental health and learning disability services.

9.4 This Chapter primarily considers the service arrangements for adults with mental illness or severe personality disorder. Services for women and for people with learning disability are considered in greater detail in Chapter 11 and Chapter 10 respectively.

THE SERVICE USERS

9.5 The DHSSPS (2003)[43] proposed that the client group for community forensic services would be defined as:

"People with a categorical mental illness, severe personality disorder or who engage in dangerous or persistently challenging, aggressive behaviour and who may be in contact with the Criminal Justice System."

9.6 A submission to the Forensic Mental Health Services Managed Care Network in Scotland[44] has proposed the following definition:

"People suffering, or appearing to suffer, from a major mental disorder whose behaviour brings them into the Criminal Justice System and are a cause for concern; either because

of the seriousness of the offence or their potential dangerousness. In addition the service will also offer input to those with severe mental disorder who pose a risk to the safety of others, but may not necessarily have been convicted of an offence".

9.7 It is apparent from definitions such as these that there can be no precise or exact cut-off point between those service users who may fall within the remit of community forensic services and those who fall within the remit of other interconnected services. There is a need for local agreement between service providers that takes account of the functions and capacities of the relevant services and ensures that the needs of service users are met.

BACKGROUND

9.8 Two models of community forensic services have been described[45] - the integrated model (forensic specialists working within community mental health teams) and the parallel model (forensic specialists working on a separate specialist team). Characteristics of both models are shown in the Table below.

Characteristics of parallel teams	**Characteristics of integrated teams**
Own team base Separate referral meetings Specialist management line Specialist supervision Protected funding Forensic psychology Good links with Criminal Justice Systems Capped caseloads	Close links with community mental health services Acceptance of more referrals from primary care

9.9 In practice many services have developed features of both parallel and integrated models.

Current Services

9.10 Until 2003-4, Community Forensic Services in Northern Ireland were very limited - they have been described by McCall (2005)[1]. In 2004 funding was allocated for the partial development of community forensic services in each of the 4 Health and Social Services Boards. It was recommended that the Community Forensic Teams ('CFTs') would work in a 4 level model:

"Level 1 - a one off assessment/consultation with the CFT;

Level 2 - a short period of assessment by the CFT with the referring team retaining responsibility;

Level 3 - agreed period of shared responsibility - (a) to assess risk, (b) to evaluate interplay/operation of known risk factors, and (c) to assess efficacy of risk reducing strategies;

Level 4 - CFT taking full responsibility for duration of need;

It would be assumed that the majority of CFT's work would be at level 1 with only a small minority at level 4".

DISCUSSION AND RECOMMENDATIONS

Standard 1. A Co-Ordinated Joint Strategic Approach

9.11 As with other components of Forensic Services it is proposed that community forensic services should be developed in a planned strategic manner by partnerships comprising service users and carers, commissioners and providers of services, representatives from forensic and interconnecting mental health and learning disability services and from Criminal Justice Agencies in the statutory, voluntary and community sectors, and also representatives from the wider community. It is expected that the Regional Forensic Network will lead and co-ordinate the planning and development of community forensic services.

9.12 The development of capacity to meet the needs of service users in the community must include both supporting and building upon the capabilities of current services, as well as developing and integrating new specialist services.

Recommendation

104. The Regional Forensic Network should lead and co-ordinate the planning and development of community forensic services. It should both support and build upon the capabilities of current services as well as developing and integrating new specialist services.

Standard 2. Evidence, Principles and Purposes

9.13 It will be essential to ensure that the plans for community forensic services have explicit purposes that take full account of the needs of all the interested parties, including the needs of service users and carers, other mental health and learning disability services and also the Criminal Justice System. Community forensic services must be planned on a multi-disciplinary and interagency basis and their purposes should include:

- assessing local referrals to secure inpatient services;
- supporting the discharge of service users from inpatient secure services to the community, facilitating self management, opportunities for employment and engagement in social activities;
- working jointly with other mental health and learning disability services to provide consultation, assessment, and support and, in some cases, shared or sole treatment and care;
- liaison with police stations and courts;
- in-reach to prisons and support of discharged prisoners with mental disorder;
- assessments at the request of probation;

- input to offender therapy programmes; and
- supporting the work of the Multiagency Procedures for the Assessment and Management of Sex Offenders (MASRAM) or its successor.

9.14 The current information on need is inadequate and systems must be devised to regularly assess need as well as the performance of services and their impact on need. The DHSSPS[43] noted in 2003 that comprehensive assessment of need *"would....be time consuming, and for the purpose of consideration of service model proposals any benefits that would be achieved over using .....(current) estimates ..... may not outweigh the delays incurred, especially as starting from such a low baseline service any developments may well be incremental and thus offer the opportunity for more accurate ongoing assessment of service demand."*

9.15 At the time of writing this Report the CFT's are not fully staffed or developed. The Review supports the current DHSSPS plans to initially develop 5 CFT's in Northern Ireland which equates to approximately one CFT per 350,000 of the population (in one or more cases 2 teams may amalgamate to form one enlarged team). It is recommended that these teams are supported by workforce planning and funding that they can reach full operating capacity as soon as possible.

9.16 It is recommended that the Regional Forensic Network commissions assessments of need to guide further planning and development. In particular it should be noted that the need for forensic services is recognised to be substantially greater in urban rather than rural areas[27]. Further developments are likely to require that services are aligned more closely to need rather than being provided on a simple *per capita* basis. The assessment of need must include not only the staffing requirements, but also resources such as accommodation suitable to meet the needs of service users. There is a need to assess the types of accommodation required and also the most appropriate locations to best meet the needs and wishes of service users and carers.

Recommendations

105. The 5 CFT's that are currently partly staffed and funded require the necessary funding and workforce planning from the DHSSPS to ensure they are developed to full operational capacity by 2010. Thereafter teams should be developed in response to need to ensure that they have capacity to fulfill the range of services required by service commissioners and service users.

106. Commissioners must commission a full range of community forensic services with the following purposes:

    - assessing local referrals to secure inpatient services;
    - supporting the discharge of service users from inpatient secure services to the community, facilitating self management, opportunities for employment and engagement in social activities;
    - working jointly with other mental health and learning disability services to provide consultation, assessment, and support and, in some cases, shared or sole treatment and care;

- liaison with police stations and courts;
- in-reach to prisons and support of dischaged prisoners with mental disorder;
- assessments at the request of probation;
- input to offender therapy programmes; and
- supporting the work of the MASRAM or its successor.

107. The CFT' s should produce information on their workload and performance which, combined with needs assessments should help guide the future planning of CFTs' including suitable accommodation in the community.

Standard 3. Organisational Structures and Interconnections

9.17 Community forensic services will need to work closely with other forensic services, with primary care services and with all other mental health and learning disability services including particularly:

- adult mental health including Community Mental Health Teams, Home Treatment/Crisis Resolution services and Assertive Outreach services, the psychotherapy services and the special needs services;
- alcohol and substance misuse;
- learning disability; and
- child and adolescent mental health services.

9.18 It will be important to consider the key linkages between the developing CFT's and secure inpatient forensic services in order to maximise joint working and to facilitate timely discharge of service users to the community.

9.19 In addition community forensic services will need to establish appropriate linkages with components of the Criminal Justice System such as:

- Police stations;
- Courts;
- Prison;
- Probation; and
- MASRAM or its successor (see Chapter 11).

9.20 Community forensic services will require a range of suitable accommodation to meet the needs of service users. These will include[27]:

- 24-hour nursed care;
- Hostel; and
- Independent community placements.

9.21 In addition there will be a requirement for day care facilities to provide a range of therapies and activities to ensure the provision of a purposeful day.

Service Models

9.22 The model currently being implemented in Northern Ireland is of CFTs working according to the model described at 9.10.

9.23 The Review places emphasis on flexible and dynamic groups of statutory, voluntary and community sector services being formed or dissolved in accordance with the needs of service users and carers. Services must work across organisational boundaries to address needs rather than being structured rigidly into organisational groupings.

9.24 All staff will require the ability to work in complementary and often overlapping roles. While emphasising the need for staff to work flexibly in response to need, there must also be careful co-ordination between CFT members to ensure there is clear agreement on the roles, responsibility, accountability and lines of communication of each member of staff.

9.25 The development of these services will require improvements in inter-agency communication and co-working to ensure that staff understand their respective roles and responsibilities and that they co-ordinate their efforts to meet the needs of service users and carers. There will be a need for joint policies, protocols and procedures on issues such as working in partnership and information sharing. There may also be a need for shared or interconnected information technology systems.

Service Capacity

9.26 It will be important to agree with all relevant parties the expected workload and capacity of each CFT. It would be easy for CFTs to become overwhelmed by large numbers of referrals from the many potential sources so that they became unable to provide the quality of service required.

9.27 It is proposed that the CFTs will spend a substantial proportion of their time working in support of other services and that the numbers of individuals for whom the CFTs have primary responsibility for treatment and care will be kept small.

Recommendation

108. Community Forensic Services should develop specific service models and structures and agreed methods of working with interconnecting services.

Staffing

9.28 It is recognised that the exact remit and workload of CFT's will vary with local circumstances. Nevertheless, the Review recommends the following as an appropriate typical composition for a CFT, as an indication of the resources required.

Recommendation

109. A CFT should comprise a range of staff with the necessary skills to meet the needs of users and carers. The following is considered representative of the skills and funding levels required:

1	Consultant Forensic Psychiatrist
1	Consultant Chartered Forensic Psychologist
1	Forensic Psychologist
1	Psychotherapist
2	Social Workers
1	Occupational Therapist
5	Nurses
2	Administrative Staff

User and carer advocacy services

The composition of CFTs should be adjusted in response to information on need and service performance.

Standard 4. Comprehensive and Accessible Services

9.29 As community forensic services develop they will need to agree arrangements for their core activities such as the gathering of information, assessment of needs, the assessment and management of risk and the provision of a range of therapies. There are particular needs to develop and maintain psychotherapeutic expertise in the assessment and treatment of these challenging service users. It is recommended that the Regional Forensic Network facilitates co-ordination of these developments, both within Northern Ireland and with other similar services outside the province.

Recommendation

110. The Regional Forensic Network should co-ordinate the development and delivery of community forensic services, including the development of policies, procedures and protocols.

Standard 5. Risk Assessment and Management

9.30 Community forensic services should develop risk assessment and management policies, procedures and protocols that should draw upon best practice and co-ordinate with the arrangements of interconnecting services.

Recommendation

111. The Regional Forensic Network should co-ordinate the development of risk assessment and management policies, procedures and protocols by community forensic services.

Standard 6. Quality Assurance

9.31 Community forensic services must have robust and demonstrable quality assurance mechanisms that involve service users and carers and include setting standards and assessing the quality of services. These should include internal mechanisms such as audit and also external review. Performance standards should include the quality of information-gathering, compliance with values and principles, and capacity to meet the needs of service users and carers, other mental health and learning disability services and Criminal Justice Agencies.

Recommendation

112. The Regional Forensic Network should promote and co-ordinate the development of performance and quality standards for community forensic services and ensure that there are robust quality assurance mechanisms including internal audit and independent external inspection and review.

Standard 7. Mental Health Promotion and Education

9.32 Community forensic services should contribute to wider programmes of mental health promotion and public education.[84]

Recommendation

113. The Regional Forensic Network should co-ordinate with the regional body with responsibility for mental health promotion to ensure that community forensic services contribute to mental health promotion and public education.

Standard 8. Information, Research and Innovation

9.33 Community forensic services should develop information strategies that include contributing to evidence-gathering, research and innovation. Information Technology should be used where appropriate to enhance service quality and delivery.

Recommendation

114. The Regional Forensic Network should co-ordinate the development of information and research strategies for community forensic services. It should promote the use of information technology to support and enhance multi-disciplinary and inter-agency communication and information-sharing, in accordance with agreed protocols.

Standard 9. Recruitment, Retention and Developing a Skilled Workforce

9.34 Staff will require training to ensure a broad range of relevant competencies to meet the needs of service users and carers and to comply with agreed policies, protocols and procedures. There are needs to develop skills in forensic psychotherapy, in offender therapies and in risk assessment and management. There are also needs for interagency training.

9.35 At the time of writing this Report, shortages of key trained staf have prevented community forensic services from developing to full capacity , thus demonstrating the crucial importance of developing workforce strategies to ensure the recruitment, training and retention of all the necessary staff to support service developments.

Recommendation

115. The DHSSPS must ensure that development and maintenance of community forensic services is supported by robust workforce planning and provision of opportunities for staff to avail of learning, development and support.

Standard 10. Sustainable and Transparent Funding

9.36 The development and maintenance of community forensic services requires appropriate funding from the relevant agencies in accordance with a long term plan that ensures sustainable development of services. There must be mechanisms that demonstrate that monies made available to services have reached their intended targets.

Recommendation

116. The development of community forensic services requires additional sustainable funding from the relevant sources. Funding arrangements must support the joint co-ordinated planning and delivery of services. There should be mechanisms to demonstrate that monies made available to services have reached their intended targets.

CHAPTER 10

FORENSIC LEARNING DISABILITY SERVICES

INTRODUCTION

10.1 People with learning disability are among the most vulnerable individuals who come into contact with the Criminal Justice System and the Mental Health and Learning Disability Services. These individuals may experience fundamental difficulties in comprehending and communicating effectively with the world around them. Some individuals also present substantial risks of causing serious harm to themselves or to others.

10.2 Despite these vulnerabilities and risks, dedicated forensic services for people with a learning disability in Northern Ireland are very limited and those services that are available are primarily inpatient based.

10.3 Recommendations in relation to forensic services for people with a learning disability have been included in Chapter 3 (Police Stations), Chapter 4 (Bail), Chapter 5 (Courts), Chapter 6 (Prisons) and Chapter 7 (Probation). In addition Chapter 11 (Specific Issues) also relates to forensic service users with a learning disability. The current Chapter relates primarily to the provision of specialist Forensic Learning Disability Inpatient and Community Services. This Chapter should also be read in conjunction with the Equal Lives Report[85] which gives broader recommendations on services for people with a learning disability.

10.4 It is difficult to estimate the prevalence of offending by people with a learning disability with any degree of accuracy. Walker and McCabe (1973)[46] indicated that, as a result of deficits in intelligence and social skills, people with a learning disability are probably more likely to be apprehended by the police than other offenders. Generally, however, studies show large variations in rates depending on inclusion criteria, types of assessment, sample type, study design and methodology. Additionally it is not clear whether people with learning disability are over or under represented in the offender population, or indeed if offending is more prevalent among people with a learning disability than in the general population (Davy, 1993[47]; Simpson and Hogg, 2001[48]).

INPATIENT SERVICES

INTRODUCTION

10.5 Recent research (Slevin et al, 2005[49]) conducted in Northern Ireland has shown that up to 65% of admissions to a learning disability hospital had been attributable to some form of severe challenging behaviour. Whilst not all this behaviour would be classified as offending behaviour a significant proportion is likely to fall into this category.

CURRENT SERVICES

10.6 Northern Ireland is served by 3 learning disability hospitals. The Northern & Eastern Health and Social Services Board areas are served by Muckamore Abbey Hospital, the

Southern Board by Longstone Hospital and the Western Board by Lakeview Hospital. Muckamore Abbey Hospital provides an inpatient forensic service mainly to the Eastern and Northern Boards, although historically it also has a regional inpatient function of admitting patients who are subject to Part III of the Mental Health (Northern Ireland) Order 1986[11]. However, there are currently marked difficulties in obtaining places at Muckamore Abbey Hospital due to a lack of rehabilitation services and supporting community services that would promote the return of service users to the community . This situation is highly unsatisfactory as it results in some service users being denied admission to the service they require and other service users being kept in hospital and unduly restricted longer than their condition requires.

10.7 A 19 bed dedicated inpatient forensic unit will open at Muckamore Abbey Hospital in 2006. The unit will provide medium and low secure services. Currently there are no low secure beds on the other learning disability hospital sites.

10.8 Service users with learning disability who require treatment in conditions of high security are transferred to the State Hospital, Carstairs, although there are currently unacceptable delays in the transfer of unsentenced prisoners (see Chapters 6 and 8).

DISCUSSION AND RECOMMENDATIONS

Standard 1. A Co-Ordinated Joint Strategic Approach

10.9 The development and delivery of comprehensive forensic learning disability services requires contributions from many sources including service users and carers, commissioners and providers of services, representatives from forensic and interconnecting mental health and learning disability services and from Criminal Justice Agencies and both the statutory and non-statutory sectors, and also representatives from the wider community . A shared strategic and proactive approach must be adopted that ensures that needs for high, medium and low levels of security are met by the provision of a range of services. It is recommended that services are co-ordinated by the Regional Forensic Network and the Learning Disability Implementation Group. These bodies should co-ordinate with other forensic services outside of the province such as the Scottish Forensic Mental Health Services Managed Care Network and with the State Hospital, Carstairs.

Recommendation

117. The Regional Forensic Network should lead the development of forensic learning disability services in Northern Ireland, in co-ordination with the Learning Disability Implementation Group. Forensic Learning Disability Services should link with forensic services outside the province, including the State Hospital Carstairs and the Scottish Forensic Mental Health Services Managed Care Network. Co-ordinated services must be planned and developed to meet the short, medium and longer term needs of service users at high, medium and low levels of security.

Standard 2. Evidence, Principles and Purposes

10.10 It is essential that all service users have access to assessment, treatment and care in conditions of high, medium or low security as their condition requires. At present, however, there are restrictions on the transfer of certain patients from Northern Ireland to conditions of high security (see Chapters 6 and 8). Similarly the lack of rehabilitation and "step down" services results in service users staying for longer periods in conditions of higher security than their clinical condition requires. A needs assessment and service mapping should be commissioned to examine the requirements for secure provision for forensic service users with learning disability . The results of this exercise should lead to the construction of a plan for a comprehensive range of forensic learning disability services at high, medium and low levels of security for service users with short, medium and longer term needs. The plan should take account of both current and future needs and should allow for the placement of service users in the most appropriate facility in accordance with their need, rather than being constrained or delayed by the lack of available places. Rehabilitation of service users will also require the provision of a range of community facilities including day care services.

Recommendations

118. The needs assessment and service mapping exercise advocated at 8.28 and 9.17 should include a detailed assessment of the needs for forensic learning disability services. This should lead to the development of a comprehensive plan and the development of a full range of inpatient and community forensic learning disability facilities and services. The Review advocates the provision of additional high and medium security services for people with learning disability in the proposed new unit (Recommendation 83). There is also a need for local low security services and community forensic learning disability services.

119. The forensic learning disability services in Northern Ireland are currently so patently inadequate that their initial development does not need to await the completion of a needs assessment exercise. A regional forensic learning disability service should be developed immediately which supports the further development of 5 localised and regionally co-ordinated teams.

Standard 3. Organisational Structures and Interconnections

10.11 The secure inpatient services at Carstairs and Muckamore Abbey Hospital must co-ordinate closely with other inpatient learning disability services, with community forensic learning disability services, with mental health services and with the prisons, probation and other components of the Criminal Justice System. There are particular needs to identify prisoners who are suffering from learning disability and who require transfer to inpatient facilities. At present there are substantial obstacles to the transfer of prisoners with learning disability to inpatient facilities. Uncertainty about the meaning of the term "severe mental handicap" under the Mental Health (Northern Ireland) Order 1986[11] has led to service providers in Scotland becoming reluctant to accept service users from Northern Ireland in case they cannot be returned at a later date. The lack of step-down facilities to support secure inpatient services in Northern Ireland has led to places becoming unavailable to other service users in acute need, including individuals who are inappropriately placed in prison.

Recommendations

120. Commissioners of mental health and learning disability services to the prisons should ensure that arrangements facilitate the early identification and transfer of people who require assessment, treatment and care in forensic learning disability inpatient services.

121. The DHSSPS must address the current obstacles to service users with learning disability receiving inpatient care, including uncertainty over the definition of the term "severe mental handicap" and the lack of step-down services at low security and in the community.

Standard 4. Comprehensive and Accessible Services

10.12 Forensic services for people with learning disability should assess the full range of biological, psychological and social needs and should provide services to meet those needs in accordance with best practice. There are particular needs to develop psychotherapeutic approaches. Services should be developed and delivered in a manner that promotes openness and good communication between all relevant people, while respecting the rights of the individual for privacy and confidentiality. Appropriate information should be provided to service users and carers. Information sharing protocols and other joint working protocols should be developed between forensic learning disability services, the Criminal Justice System and other mental health and learning disability services.

Recommendation

122. The Regional Forensic Network should promote the development of joint working policies, procedures and protocols between forensic learning disability services and interconnecting mental health and learning disability services and services in the Criminal Justice System.

Standard 5. Risk Assessment and Management

Recommendation

123. The Regional Forensic Network should promote the development by forensic learning disability inpatient services of risk assessment and management polices, procedures and protocols that co-ordinate with mental health services and with the Criminal Justice System (see Chapter 11).

Standard 6. Quality Assurance

10.13 Forensic learning disability inpatient services should develop robust systems to assess performance and assurance quality and clinical governance. One of the criteria used to assess the efficacy of forensic learning disability inpatient services should be their capacity to take service users at short notice, including prisoners in need of assessment, treatment and care. Services should analyse the constraints to the progress of service users and should formulate plans to remove or overcome the obstacles that are identified.

Recommendation

124. The Regional Forensic Network should co-ordinate the development of robust systems to assess performance and assure quality and clinical governance for forensic learning disability inpatient services.

Standard 7. Mental Health Promotion and Education

Recommendation

125. The Regional Forensic Network should co-ordinate with the regional body with responsibility for mental health promotion to facilitate the contribution of secure forensic learning disability inpatient services to mental health promotion and public education.

Standard 8. Information, Research and Innovation

10.14 Services should develop an ethos of inquiry that promotes information gathering, research and innovation. They should be supported by internal organisational structures. Information technology systems should be developed to support service planning and delivery and co-ordination of information sharing.

Recommendations

126. The Regional Forensic Network should co-ordinate the development of information systems and research in forensic learning disability services.

127. The Regional Forensic Network should promote the integration of InformationTechnology systems between forensic learning disability services and interconnecting services to help ensure the effective transfer of information.

Standard 9. Recruitment, Retention and Developing a Skilled Workforce

10.15 The development and maintenance of forensic learning disability services must be supported by workforce planning strategies and mechanisms that ensure the recruitment and retention of staff who are equipped with the appropriate personal qualities and professional qualifications. There must be learning and development arrangements to provide staff with the necessary knowledge, skills, support and opportunities for further learning, professional and personal development. The needs for learning and development include not only staff working in forensic learning disability services, but other staff working in interconnecting health and social services and in Criminal Justice Agencies. Forensic learning disability services must co-ordinate with other services to meet their general and specific learning and development needs.

Recommendation

128. The DHSSPS must ensure that development and maintenance of forensic learning disability inpatient services is supported by robust workforce planning and provision of opportunities for staff to avail of learning, development and support.

Standard 10. Sustainable and Transparent Funding

Recommendation

129. The development and maintenance of forensic learning disability services requires appropriate funding from the relevant sources. Funding should be delivered in accordance with long-term plans that ensures sustainable development of services. Funding arrangements must support the joint co-ordinated planning and delivery of services. There must be mechanisms that demonstrate that monies made available to services have reached their intended targets.

COMMUNITY FORENSIC LEARNING DISABILITY SERVICES

CURRENT SERVICES

10.16 At present there are no dedicated forensic services for people with learning disability in the community in Northern Ireland. For those individuals whose needs have been identified and who are currently receiving services, they may receive them from various sources including Community Learning Disability Teams (CLDT's), Behaviour Support Services (BSS), psychology services or from Autistic Spectrum Disorder (ASD) services for adults.

Standard 1. A Co-Ordinated Joint Strategic Approach.

10.17 The development of capacity to meet the needs of service users in the community must include both supporting and building upon capabilities of current services as well as developing and integrating new specialist services. As with other components of forensic services, community forensic learning disability services should be developed in a strategic manner through inclusive partnerships. It is proposed that the Regional Forensic Network, in partnership with the Learning Disability Implementation Group, co-ordinates the planning and development of community forensic learning disability services. Service providers will need to develop and maintain specialist expertise in assessing and providing treatment to forensic service users with learning disability. This will require and, at times, joint working with community forensic service providers.

Recommendation

130. The Regional Forensic Network should liaise with the Learning Disability Implementation Team and take the lead role in promoting the planning and development of community forensic learning disability services.

Standard 2. Evidence, Principles and Purposes

10.18 Community forensic learning disability services should be developed in accordance with the principles advocated by this Review and services should have clear explicit purposes. Service planning must be informed by detailed assessment of need.

Recommendation

131. The proposed needs assessment and service mapping exercise (Chapter 8) should include the gathering of information to guide the further development of community forensic learning disability services, following the initial development of a regional service.

Standard 3. Organisational Structures and Inter-Connections

10.19 Community forensic learning disability services must work closely in co-ordination with all interconnecting services including inpatient services, Criminal Justice Agencies and mental health services. Community forensic learning disability services will need to develop close connections with police stations, courts, prisons, probation and MASRAM. Community forensic services will require a range of suitable accommodation to meet the needs of service users, including:

- 24 hour nurse care;
- hostels; and
- independent community placements.

10.20 Services will also require a range of day care facilities.

10.21 As with community forensic services, it is expected that community forensic learning disability services will adopt a tiered approach. It will be important to agree with all relevant parties the expected workload and capacity of each team.

Recommendation

132. Immediate measures should be taken to create a regional community forensic learning disability service linked to an inpatient assessment and treatment service. This regional service should support the development of 5 locally based and regionally co-ordinated community forensic learning disability teams. These teams must have sufficient capacity to fulfill the same purposes as those identified for other community forensic services (Chapter 9).

Standard 4. Comprehensive and Accessible Services

10.22 Community forensic learning disability services should co-ordinate with interconnecting services to provide a comprehensive range of timely , accessible and high quality services that assess needs and provide treatment and care for service users and support for their carers with continuity of services for as long as required.

Recommendation

133. Community Forensic Learning Disability Teams must be developed with the necessary staffing levels and range of skills to meet the needs of users and carers. The proposed regional team is likely to require similar staffing levels and resources to the Community Forensic Teams proposed at Chapter 9, with the addition of access to speech and language therapy services.

Standard 5. Risk Assessment and Management

Recommendation

134. The Regional Forensic Network should ensure that community forensic learning disability services in Northern Ireland develop risk assessment and management policies, procedures and protocols that represent best practice and co-ordinate with the arrangements of interconnecting services.

Standard 6. Quality Assurance

Recommendation

135. The Regional Forensic Network should promote and co-ordinate the development of performance and quality standards for community forensic learning disability services and ensure that there are robust quality assurance mechanisms including internal audit and independent external inspection and review.

Standard 7. Mental Health Promotion and Education

Recommendation

136. The Regional Forensic Network should co-ordinate with the regional body with responsibility for mental health promotion to ensure that community forensic learning disability services contribute to mental health promotion and public education.

Standard 8. Information, Research and Innovation

10.23 Community forensic learning disability services should contribute to evidence gathering and promote research and innovation. Information technology should assist the development and delivery of services and should co-ordinate with interconnecting services.

Recommendation

137. The Regional Forensic Network should co-ordinate the development of information and research strategies for community forensic learning disability services. It should promote the use of information technology to support and enhance multi-disciplinary and inter-agency communication and information-sharing, in accordance with agreed protocols.

Standard 9. Recruitment, Retention and Developing a Skilled Workforce

10.24 As with other forensic services, community forensic learning disability services require robust recruitment and retention procedures and learning and development systems that ensure the provision of a skilled workforce.

Recommendation

138. The DHSSPS must ensure that development and maintenance of community forensic learning disability services is supported by robust workforce planning and provision of opportunities for staff to avail of learning, development and support.

Standard 10. Sustainable and Transparent Funding

Recommendation

139. The development of community forensic learning disability services requires additional sustainable funding from the relevant sources. Funding arrangements must support the joint co-ordinated planning and delivery of services. There should be mechanisms to demonstrate that monies made available to services have reached their intended targets.

CHAPTER 11

SPECIFIC ISSUES

INTRODUCTION

11.1 This Chapter examines 5 further issues that have been identified as requiring particular attention in order to promote the development of comprehensive forensic services in Northern Ireland. These are:

(i) The Assessment and Management of Risk;
(ii) Personality Disorder;
(iii) Autistic Spectrum Disorder;
(iv) Services for Women; and
(v) Forensic Psychotherapy.

11.2 It is recognised that potentially a great number of other special groups could be considered, such as Forensic Service Users with eating disorders, acquired brain injury, deafness or adult Attention Deficit and Hyperactivity Disorder. Ultimately each forensic service user is an individual with unique needs. Thus the Review has recommended a flexible model of services that is built upon assessing the needs of each individual service user and his or her carers and then providing services to address those needs. As forensic services are developed and new scientific discoveries are made, there will be a continuing need to review services to ensure they properly meet the needs of individual and groups of service users and carers.

THE ASSESSMENT AND MANAGEMENT OF RISK

1) Introduction - Developments in Forensic Services and Criminal Justice

11.3 The assessment and management of risk is one of the central activities of forensic mental health and learning disability services and of the Criminal Justice System. In Northern Ireland and other parts of the United Kingdom there have recently been important developments in Criminal Justice in relation to the management of risks posed by violent and sexual offenders. These developments in Criminal Justice extend beyond the remit of the Review, which is concerned with making recommendations in relation to people suffering from mental disorder, but they are relevant to the assessment and management of some mentally disordered offenders and also to the development of interagency practices at the interfaces between criminal justice and health and social services agencies.

i) Multi-Agency Public Protection Arrangements (MAPPA)

11.4 In England and Wales, the Criminal Justice and Court Services Act (2000)[50] established the Multi-Agency Public Protection Arrangements (MAPPA) which were re-enacted and strengthened by the Criminal Justice Act (2003)[51]. These require the police, prison and probation services to work together to assess and manage the risks posed by sexual and violent offenders. Multi-Agency Protection Panels (MAPPs) have 4 main functions:

- identification of mappa offenders;
- sharing of relevant information;
- assessment of risk of serious harm; and
- management of risk of serious harm.

ii) Multi-agency Procedures for the Assessment and Management of Sex Offenders (MASRAM)

11.5 In Northern Ireland Multi-agency Procedures for the Assessment and Management of Sex Offenders (MASRAM) were launched in 2001. At present MASRAM is an interagency response to sex offending that comprises four core agencies – the Police Service, the Probation Board, the Prison Service and Social Services. It is an administrative arrangement and does not have a statutory basis. The Criminal Justice Inspection (Northern Ireland) reviewed MASRAM (2005)[52] and recommended that it should be placed on a statutory footing with guidance to underpin its activity, that its remit should be extended to include violent offenders and that it should organise its activities to target those posing the highest levels of risk. The report also recommended that the process for discharging restricted hospital patients should incorporate a thorough criminal justice risk assessment and plan for appropriate post-discharge support.

iii) Review of the Sentencing Framework in Northern Ireland

11.6 The Northern Ireland Office has published a consultation document on the Review of the Sentencing Framework (2005)[53]. Options discussed include wider use of compulsory supervision following custody, a discretionary release to ensure that dangerous offenders are not released until their risk is such that they can be safely supervised in the community and mechanisms to ensure that a released offender can be rapidly recalled to prison if he either causes harm or evidences the likelihood that he will cause harm.

iv) Life Sentence Review Commission

11.7 In Northern Ireland, the Life Sentence Review Commission is an independent judicial body which considers the release of life sentence prisoners once the tariff period is completed. Prisoners must satisfy the panel that it is no longer necessary for the protection of the public from serious harm that he or she is confined. It must be established that the risk of the prisoner committing serious harm if released on licence is no more than minimal. The panel may make recommendations about licence conditions attached to the prisoner's release.

v) Risk Management Authority (RMA) and Order for Lifelong Restriction (OLR)

11.8 In Scotland there is no equivalent of MASRAM or MAPPA. The Report of the Committee on Serious Violent and Sexual Offenders chaired by Lord MacLean[54] made a series of recommendations in relation to the assessment and management of 'high risk offenders'. These included the establishment of a Risk Management Authority (RMA) and the introduction of a Risk Assessment Order that enables a formal risk assessment to be conducted after conviction and before sentencing. A new sentence, the Order for Lifelong Restriction (OLR) may be imposed on certain offenders who are assessed as presenting a substantial and continuing risk to the public. Such offenders are supervised and managed in accordance with a Risk Management Plan.

11.9 The RMA was established by the Criminal Justice (Scotland) Act 2003[55]. The remit of the RMA includes:

- developing policy and carrying out research into the risk assessment and risk management of offenders whose liberty presents a risk to the public at large;
- setting standards for and issuing guidance to those involved in the assessment and management of risk; and
- accrediting practitioners and risk management plans and monitoring risk management plans for those offenders who receive an OLR sentence from the High Court.

2) Some Concepts in Relation to the Assessment and Management of Risk in Mentally Disordered Offenders

11.10 Forensic services are concerned with mentally disordered offenders and others with similar needs. Service users pose risks of harm to themselves and others that will vary in nature and degree at different times and in different circumstances. Service providers must ensure that arrangements are put in place to identify and respond appropriately to these risks. These responses must also take into account the mental capacity of the individual and his or her responsibility and rights to self-determination.

11.11 The varying risks posed by forensic service users must be placed within the broader context of the risks posed by many other individuals in our society . There must be consistent approaches across society that identify and respond to risk, but do not discriminate unjustifiably against those suffering from mental disorder.

11.12 Risk assessment and management procedures must be evidence based and fully acknowledge the considerable limitations of current risk prediction methods. The failure to correctly predict harm (“false negative” prediction) results in missed opportunities to prevent harm if the prediction methods had been more accurate. The prediction of harm when, in fact, it would not have occurred (“false positive” prediction) can result in service users being unnecessarily restricted, for example, by being kept in hospital for longer than required[56]. Such false positive predictions may also incur unnecessary and substantial public financial expenditure.

11.13 There are dangers that a ‘culture of blame’ will lead to an unwarranted preoccupation with risk that discriminates those with mental disorder and makes service providers reluctant to take even small risks. The concepts of risk taking and risk appetite are of fundamental importance. HM Treasury (2004)[57] has stated:

> *"The resources available for managing risk are finite and so the aim is to achieve an optimum response, prioritised in accordance with an evaluation of the risks. Some amount of risk taking is necessary – the only way to avoid risk is to do nothing at all which is guaranteed to ensure that nothing is achieved. The amount of risk which is judged to be tolerable and justifiable is the "risk appetite".*

11.14 The risk appetite of our society will be a significant influence on the overall size of developing forensic services. A relatively small risk appetite could result in the development of large forensic services, high financial costs for society and high personal costs for service users who will be subject to greater restriction and deprivation of liberty. A relatively large risk appetite would result in substantially lower public expense, service users would be rehabilitated more quickly and they would be subject to less restriction. There may be some increase in incidents of harm, although the small contribution of mental illness to the overall levels of offending indicates that the total number of such incidents is likely to be small.

11.15 Increasingly adverse incidents have come to be viewed as the outcome of a number of influencing and causal factors within systems of care. Rather than automatically blaming or scapegoating the individual service provider who last had contact with the perpetrator before an incident was committed, approaches such as root cause analysis attempt to identify and improve underlying systemic factors such as service organisation and workload, training, policies and procedures. Robust quality assurance and clinical governance mechanisms must be developed that take a proactive and systemic approach to risk assessment and management and that incorporate learning from incidents and "near-miss" events.

3) Approaches to Risk Assessment and Management

i) The Care Programme Approach and Discharge Guidance

11.16 Systematic approaches to risk assessment and management have been adopted in England and Wales and in Scotland through the Care Programme Approach[58] and the Enhanced Care Programme Approach[44]. Essentially these processes bring together the relevant parties (users, carers and service providers) at Care Programme meetings to agree the identified needs and risks and to develop co-ordinated care plans and risk management plans. The outcome of these meetings is documented and circulated to all relevant parties to ensure that there is clarity in relation to the roles, responsibilities and actions to be taken to support the treatment and care of the service user.

11.17 In Northern Ireland, the Department of Health and Social Services introduced guidance entitled "Discharge from Hospital and the Continuing Care in the Community of People with a Mental Disorder who could Represent a Risk of Serious Physical Harm to Themselves or Others". The guidance was introduced in 1996 and revised in 2004[20]. The guidance seeks to improve standards of care and has similarities to the Care Programme Approach. Although the guidance has a number of commendable features concerns have been raised that it does not adequately respect the autonomy of individual service users, that it stigmatizes those with mental disorder, that it places unrealistic expectations on service providers and that it places liability on service providers for the actions of some people who are mentally competent to take responsibility for themselves. Unlike the Care Programme Approach, it has been introduced without additional resources or training to support implementation.

ii) Clinical Practice

11.18 In practice forensic services in the rest of the United Kingdom and elsewhere have developed risk assessment and management procedures and protocols that include:

- information gathering;
- information sharing;
- risk evaluation; and
- risk management plans.

11.19 Procedures often include the systematic use of risk assessment tools that combine actuarial and clinical features and are relevant to the context of the service user. Psychodynamic assessments also assist in understanding the individual and his or her characteristic patterns of thoughts, feelings and behaviours.

4) Discussion

The Assessment and Management of High Risk Offenders

11.20 Recent developments within the Criminal Justice System have supported an interagency approach to the assessment and management of risk of violent or sexual offending. This Review seeks to promote interagency co-operation at the interfaces between Criminal Justice and Mental Health and Learning Disability Services. The Review also supports approaches to risk assessment and management in the Criminal Justice System that are applied equitably across the population and do not discriminate unjustifiably against those suffering from mental disorder.

11.21 The Review supports the development of a risk assessment and management framework to help offenders reduce their risks of offending and to protect the public from high risk offenders while restricting the freedoms of such individuals no more than is necessary in the public interest. This risk assessment and management framework should apply to all offenders who pose the prescribed level of risk and irrespective of whether these individuals suffer from mental disorder such as mental illness, severe learning disability or personality disorder, or whether there is no such mental disorder.

11.22 Such a framework is likely to interface with the work of other bodies such as MASRAM, the Life Sentence Review Commission, the proposed Parole Board and, in relation to Restriction Order patients, the Northern Ireland Office and the Mental Health Review Tribunal.

11.23 These issues relate to many areas of the Criminal Justice System and encompass many individuals who do not suffer from mental disorder. Thus they extend substantially beyond the remit of this Review. Similarly, although the Criminal Justice Inspectorate made helpful recommendations in respect of many aspects of the assessment and management of the risks posed by offenders, the remit of its inspection of the MASRAM process did not include the full range of issues identified by this Review. Likewise the Review of Sentencing Framework has considered some issues such as sentencing options for dangerous offenders, but these have not been integrated into a comprehensive framework for Northern Ireland. This Review recommends that these elements are drawn together by another body which comprises the relevant stakeholders and considers the range of options and measures required to produce a comprehensive interagency and community response to help offenders reduce their risks of offending and to provide protection to the public from high risk sexual and violent offenders.

11.24 The Review supports the creation of a service, run jointly by the Criminal Justice System and the HPSS the assessment and management of high risk offenders. It envisages a joint co-operative response to offenders that assesses the needs of each individual, his or her carers and also takes account of the needs of the public for protection. The Review recognises that in order to reduce the risk to the public to acceptable levels there may be a requirement for some offenders to be treated, managed or placed in specialised institutional settings. The Review envisages a range of services including a high secure facility, one of more facilities at lower levels of security and also services in the community. Offenders would be admitted to such facilities not primarily on the basis of mental disorder, but rather because of the risk they pose to public safety. These services would be similar to the pilot therapy programmes that have been developed for high risk offenders in England.

Recommendation

140. The DHSSPS and the Northern Ireland Office and relevant Criminal Justice Agencies should produce a comprehensive interagency and community response to help offenders reduce their risks of offending and to provide protection to the public from high risk sexual and violent offenders, irrespective of whether or not they suffer from mental disorder. This Risk Assessment and Management Framework should include:

- the legislative framework, including options to provide courts with risk assessments such as a risk assessment order and sentencing options such as an order for lifelong restriction;
- processes, methods and standards of risk assessment, risk management and offender therapy programmes;
- interagency strategies and working arrangements, including information sharing and other joint protocols and procedures;
- development of best practice, guidance and quality assurance mechanisms;
- training in risk assessment, risk management and offender therapy methods;
- accreditation of practitioners;
- the services required for the assessment and management of risk and the provision of offender therapies, including specialist facilities in conditions of security and in the community;
- the development of research strategies and methods of research and evaluation; and
- assessment of the workforce requirements and the provision of appropriate workforce planning and funding to meet the identified needs.

The Assessment and Management of Mentally Disordered Offenders

11.25 Forensic Mental Health and Learning Disability Services in Northern Ireland should develop standardised risk assessment and procedures and management protocols in relation to:

- information gathering;
- information sharing;
- risk evaluation; and
- risk management plans.

11.26 These should be co-ordinated by the Regional Forensic Network and integrate with the proposed Risk Assessment and Management Framework and with local clinical governance arrangements. They must recognise what can reasonably be achieved within the resources available and set standards that are monitored.

Recommendations

141. The Regional Forensic Network should ensure that all inpatient and community forensic services in Northern Ireland develop risk assessment and management policies, procedures and protocols that represent best practice and co-ordinate with the Risk Assessment and Management Framework.

142. The Regional Forensic Network should promote and co-ordinate the development of performance and quality standards for risk assessment and management by forensic services and ensure that there are robust quality assurance mechanisms including internal audit and independent external review.

143. The DHSSPS should revise current Discharge Guidance to ensure that it is compatible with the principles recommended by this Review and is supported by training and other appropriate resources.

PERSONALITY DISORDER

Introduction

11.27 Personality disorder is a major source of suffering for individuals and those in contact with them. It is also perhaps the most controversial, emotive and poorly understood issue at the interface between the Criminal Justice System and the Health and Social Services. The recommendations in this section interlink with those contained in many other parts of this Report but, it was considered fundamentally important to focus specifically on the issue of personality disorder in order to promote a positive and coherent vision for the future development of services, based on a partnership approach.

Definitions

11.28 The World Health Organization (WHO) (1992)[59] has defined personality disorder as:

> *"Deeply ingrained and enduring behaviour patterns, manifesting themselves as inflexible responses to a broad range of personal and social situations. They represent either extreme or significant deviations from the way the average individual of a given culture perceives, thinks, feels and particularly relates to others. Such behaviour patterns tend to be stable and to encompass multiple domains of behaviour and psychological functioning. They are frequently, but not always, associated with various degrees of subjective distress and problems in social functioning and performance".*

11.29 The WHO (1992)[59] has classified specific personality disorders into:

- Paranoid;
- Schizoid;
- Dissocial;
- Emotionally unstable – impulsive type;
- Emotionally unstable – borderline type;
- Histrionic;
- Anxious (avoidant);
- Anankastic;
- Dependent; and
- Others.

11.30 The majority of specific personality disorders are not related to an increased likelihood of offending. Rates of personality disorder are high among certain groups of offenders, for example Singleton (1998)[60] found that 78% of male remand prisoners had personality disorder.

11.31 Mental illness is diagnosed on a separate axis or dimension from personality disorder. There is no objective measure of personality disorder and no clearly defined cut-off between normal and abnormal personality. An individual can be diagnosed as suffering from several personality disorders. Combinations of diagnoses are not uncommon in forensic practice, for example an individual may be diagnosed as suffering from schizophrenia, dissocial personality disorder and alcohol dependence syndrome.

11.32 In order to make a diagnosis of personality disorder a detailed process of assessment is required that considers the account and presentation of the individual and also generally additional information from other sources, for example, family members, health and social services and Criminal Justices Agencies. Structured and standardised psychological assessment may aid the diagnostic process. Personality disorder should not be diagnosed on the basis of specific behavioural problems alone, but rather there must be detailed consideration of the individual's characteristic patterns of perceiving, thinking, feeling and relating to others. In current clinical practice in Northern Ireland a lack of standardised approaches to the diagnosis of personality disorder means that the diagnosis may be made without adequate information or the diagnosis may be missed, for example when personality disorder is present in addition to other mental disorders such as mental illness or substance misuse.

11.33 It is generally considered that personality disorder is caused by a combination and interaction of genetic propensities and adverse early experiences such as abuse and neglect. Adverse experiences in adult life may also contribute to personality deterioration. Personality disorders are by definition deeply ingrained, enduring and stable and thus they are not readily amenable to change. It is, therefore, important that research is commissioned into understanding how personality disorders develop and the most effective ways of preventing them. Forensic Services should contribute to those efforts.

11.34 In Scotland the Committee on Serious Violent and Sexual Offenders[54] noted that there are many types of personality disorder , the majority of which are not related to an increased likelihood of offending. The Committee emphasised the importance of the identification and management of high risk offenders, whether personality disordered or not.

The Committee stated that:

"Present understanding does not support compulsory hospitalisation and medical treatment for severe anti-social personality disorder."

11.35 In many respects the concept of personality disorder has limited utility . The term is so broad and the different types of personality disorder may have such different manifestations that the term "personality disorder" by itself conveys little meaning. It is often more appropriate to take a problem-orientated approach, in other words, an approach that seeks to identify and modify specific behaviours or behavioural deficiencies rather than attempting to change the whole personality of the individual. Such an approach also generally reflects the wishes of service users who tend to present to services complaining of specific problems or difficulties rather than "personality disorder".

Current Services

11.36 There are no specific services for forensic service users in Northern Ireland that are dedicated to the assessment and treatment of personality disorder - there are no residential facilities such as therapeutic communities, special prison units or secure hospital units, nor are there dedicated services in the community.

11.37 Thompson and colleagues[34] have described the current situation in Scotland where "At the present time it is routine psychiatric practice in Scotland **not** to admit individuals with a primary diagnosis of personality disorder to forensic psychiatric units". Although personality disorder is specifically included in the Mental Health (Care and Treatment) (Scotland) Act 2003[37], detention under that Act requires that an individual has significantly impaired ability to make decisions about treatment. Generally people with a primary diagnosis of personality disorder are considered not to have such impairment and thus they are not considered detainable for treatment under the Scottish mental health legislation. Although community forensic mental health service provision is rudimentary in most parts of Scotland, most forensic psychiatrists have a small cohort of outpatients with a primary diagnosis of personality disorder.

11.38 In England personality disorder has been rejected as a diagnosis of exclusion [61] and there has been substantial financial investment in forensic services for people suffering from personality disorder.

11.39 The pilot schemes in England are being closely evaluated[34]. These include:

- the development of pilot inpatient and community forensic personality disorder services;
- the development of pilot units to treat people with "Dangerous and Severe Personality Disorder" - 2 units in prison and 2 units in high security hospitals; and
- the continuing use of HMP Grendon as a therapeutic community for prisoners with challenging behaviours within the prison service.

STANDARDS

Standard 1. A Co-Ordinated Joint Strategic Approach

11.40 The Review recommends a combined approach by the Criminal Justice System and Health and Social Services to the assessment and management of offenders who suffer from personality disorder. This approach must recognise the huge morbidity associated with personality disorder and the legitimate wishes of those with personality disorder and their carers to have access to assessment and treatment services.

11.41 People with personality disorder who are subject to the Criminal Justice System should not be excluded on the basis of that diagnosis from assessment or from receiving clinically appropriate therapeutic interventions by mental health and learning disability services. Similarly people with personality disorder who are subject to the Criminal Justice System should not be excluded from Criminal Justice Services, nor should assessment and management of their problems and needs be regarded as the sole responsibility of mental health and learning disability services.

11.42 The approach should ensure that the unique contributions of forensic mental health and learning disability services are utilized in assessment and treatment. The Criminal Justice System must also accept its major role in the management of offenders with personality disorder as these individuals are almost invariably considered to have criminal responsibility for their actions.

Recommendation

144. The DHSSPS and NIPS must ensure that services are developed for people with personality disorder, including offenders. The services require co-ordinated joint approaches by both the Criminal Justice System and the Health and Social Services. Service users, carers and their advocates must be involved in service planning and delivery.

Standard 2. Evidence, Principles and Purposes

11.43 The Review urges an explicit ethical basis to the assessment, treatment and care of people suffering from personality disorder. Evidence based services should be offered to individuals who wish to avail of them, whether or not they are subject to the Criminal Justice System. The Review does not consider it is ethical for mental health legislation to be used to enforce compulsory treatment on individuals who are mentally competent to refuse it.

11.44 The issue of personality disorder should not be confused with the issue of offenders who are at high risk of committing serious violent or sexual offences. The Review recognises the wishes of society to receive protection from high risk offenders and it has supported the development of a comprehensive interagency and community response, irrespective of whether or not such high risk offenders suffer from mental disorder. Society should not discriminate unjustifiably against those who suffer from mental disorder, for example, it should not introduce compulsory powers against high risk offenders who suffer from mental disorder that are more restrictive than the powers against offenders who pose an equally high level of risk, but do not suffer from mental disorder.

Standard 3 and Standard 4. Organisational Structures and Interconnections and Comprehensive Accessible Services

11.45 The Review envisages the provision of the following services for Northern Ireland:

In the community:

- residential therapeutic community facilities for forensic service users in Northern Ireland;
- day patient and outpatient services provided by each community forensic service; and
- input from each community forensic service into offender therapy programmes led by probation.

In the prisons:

- day patient and outpatient services provided in by prison forensic services; and
- input from prison forensic mental health and learning disability services to the assessment and management of prisoners attending the offender therapy programmes.

11.46 In addition consideration should be given to the development of a secure service for the management of prisoners whose personality disorder makes them unmanageable in an ordinary prison environment and those who would benefit from management in a therapeutic community. It is proposed that the Criminal Justice System and the Health and Social Services would jointly develop this service. It would offer detailed interagency and multi-disciplinary assessment, including:

- history of the individuals' life experiences;
- needs;
- mental state;
- psychological assessment;
- functional assessment;
- medical diagnoses;
- mental capacity; and
- risk assessment.

11.47 The service would require clear criteria for admission and discharge that would be subject to appeal. The service should offer a therapeutic ethos, including evidence-based therapies that are linked to research on therapeutic efficacy. The service should not offer perverse incentives to prisoners to behave in a disturbed manner with a view to securing admission to a more favourable service than the ordinary prison environment. The service would require one or more new facilities, both at high security and at lower levels of security with linkages to community services. The Review has noted the probable need for additional secure provision and this proposed new service for offenders may form a component of this additional provision. The service would need to be linked to a robust risk management framework operate according to explicit standards and be open to external inspection. The service would require high levels of psychotherapeutic input combined with high levels of training and support for staff.

11.48 At present there is not sufficient information on needs to make detailed recommendations on the size of these services.

Recommendations

145. The DHSSPS should ensure that assessment and treatment services are made available to offenders suffering from personality disorder along with support for their carers. Services should be provided in prisons and in the community. Services in the community should comprise outpatient, day patient and therapeutic community services. In the prisons outpatient and day patient services should be provided. A residential secure service should also be developed.

146. The DHSSPS should commission a detailed assessment of needs to inform the planning of services for offenders with personality disorder.

Standard 5. Risk Assessment and Management

11.49 It will be essential to support the development of these services by explicit policies on risk and responsibility. Within the current 'culture of blame'[62] guidance from the DHSSPS places responsibility on mental health and learning disability services for the actions of individuals who are mentally competent to make decisions for themselves. These obstacles to service delivery must be removed. Risk assessment and management arrangements for mentally disordered offenders should co-ordinate with those for other offenders and must not discriminate unjustifiably against those suffering from mental disorder. Also policies, procedures and protocols should be developed to take account of the needs to preserve medical confidentiality and to share information.

Recommendation

147. Service providers must ensure that services for the assessment and management of personality disorder are supported by the development of policies, procedures and protocols that recognise the respective responsibilities of all key stakeholders and that co-ordinate with the proposed Risk Assessment and Management Framework.

Standard 6. Quality Assurance

11.50 Forensic services must have robust and demonstrable quality assurance and governance mechanisms that include setting standards and assessing the quality of services. These should include internal mechanisms such as audit and also external review.

Recommendation

148. The commissioners and providers of services for offenders with personality disorder must ensure that services have strong quality assurance and governance arrangements including internal audit and independent external inspection and review.

Standard 7. Mental Health Promotion and Education

Recommendation

149. The Regional Forensic Network should co-ordinate with the regional body with responsibility for mental health promotion to ensure that forensic services for people with personality disorder contribute to mental health promotion and public education, including contributing to understanding of the development of personality disorders and the most effective ways of preventing them.

Standard 8. Information, Research and Innovation

Recommendations

150. The Regional Forensic Network should promote the development of information and research strategies for forensic services for people with personality disorder. Research should be conducted into the needs of offenders with personality disorder and into the efficacy of therapeutic interventions.

151. The Regional Forensic Network should promote the use of information technology to support and enhance multi-disciplinary and inter-agency communication and information-sharing, in accordance with agreed protocols.

Standard 9. Recruitment, Retention and Developing a Skilled Workforce

Recommendation

152. The DHSSPS must ensure that robust workforce planning systems are developed to ensure the recruitment, training support and retention of suitable staff to support the development of services for offenders with personality disorder.

Standard 10. Sustainable and Transparent Funding

Recommendation

153. The development and maintenance of forensic services for the assessment and treatment of high risk offenders and individuals suffering from severe personality disorder requires appropriate funding from the relevant agencies. This should be delivered in accordance with a long term plan that ensures sustainable development of services. There must be mechanisms that demonstrate that monies made available to services have reached their intended targets.

OFFENDING BY ADULTS WITH ASPERGER'S SYNDROME OR HIGH FUNCTIONING AUTISM (AS/HFA)

INTRODUCTION

11.51 Current trends in prevalence[63] confirm an increase in the number of individuals in the general population receiving a diagnosis of an ASD, including Asperger's Syndrome or High Functioning Autism (AS/HFA). Recommendations for services for these individuals are contained in the Strategic Framework for Adult Mental Health Services[83]. Professionals in forensic services are increasingly likely to encounter individuals with AS/HFA. There is a need to increase our understanding of the relationship between AS/HFA and offending and to improve the identification and assessment of such individuals and their management within the Criminal Justice and Health and Social Services Systems.

Prevalence of AS/HFA within Forensic Services

11.52 While the majority of persons with AS/HFA are scrupulously law abiding[64], a small subset does come into contact with the legal system. Those with AS/HFA may behave in socially deviant and destructive ways with consequent police involvement. Due to poor diagnostic expertise in many countries, it is not clear how commonly violent and potentially criminal behaviour occurs by people with AS/HFA. Kohn et al (1998)[65] suggested that the prevalence of aggression in the population of AS/HFA persons is around 20% with many cases not being reported to police authorities.

11.53 A study of 135 young offenders assessed by the Forensic Psychiatry Department in Stockholm[66] found 30% with probable AS/HFA and a strong association with arson. Scragg and Shah (1994)[67] screened the entire population of Broadmoor Hospital, finding a rate for AS/HFA of 2.3% In 1999 the National Autistic Society[68] screened 1305 patients (96% of the total population) in three Special Hospitals in England and identified 31 cases (2.4%).

There were a further 31 'equivocal' cases who displayed some features of AS/HFA, but for whom the screening process was insufficient to be definitive and they would have required a full diagnostic evaluation to obtain a certain diagnosis. Wing (2003)[69] also reported 2.4 – 5.3% prevalence in a Special Hospital population, with over half of these having a co-morbid diagnosis of schizophrenia. The prevalence of adults with AS/HFA within the prison system or detained under the mental health legislation is unknown, as is the prevalence of females with AS/HFA involved with forensic services.

11.54 In a local community service for adults with AS or HFA, 18% of the individuals had been involved with the police and/or court services for offences including stalking behaviour, sexual offences, theft, fire setting and anti-social behaviour[70]. Of the Trust's sample, 25% of individuals known to the service had been detained in a psychiatric hospital under the Mental Health (Northern Ireland) Order 1986 at some time. Out of the 6 individuals with a forensic history, 5 had been admitted, 2 of who were formally detained - but not necessarily as a direct result of their offending behaviour. None had received a prison sentence.

Relationship between AS/HFA and Offending

11.55 Direct relationships between the offending behaviour and the clinical features of the disorder have been identified, particularly deficits in social relatedness or rigidity in thought and behaviour[71]. Case reports have noted connections between offending behaviour and core impairments of AS/HFA including:

- deficient empathy and consequent failure to recognise the impact of behaviours on others;
- problems with social understanding such as reacting negatively to actual or perceived rejection and bullying;
- an over sensitivity to sensory stimuli leading to a violent reaction;
- having a rigid interpretation of rules; and
- an obsessional pursuit or interest.

11.56 Also highlighted by Wing (1997)[72] is the social naivety and lack of common sense often seen in individuals with AS/HFA, which can make them easy targets for being manipulated by others with criminal intentions and malice. Such conspicuous interpersonal idiosyncrasies make those with AS/HFA particularly vulnerable to victimisation[73].

11.57 Murrie et al (2002)[74] observed that those with AS/HFA may have little or no experience with alcohol or drugs, little previous criminal contact and may be quick to confess to the police. They stated that this last aspect reflected a variety of traits from deficient shame, poor judgement, lack of experience, or an impaired appreciation of the social and legal consequences of a confession, to simple forthrightness, rule-abiding behaviour or honesty.

11.58 Murrie et al (2002)[74] emphasised the need for full assessment of AS/HFA and its legal implications so that courts could make properly informed decisions on issues such as treatment and disposal.

Need for Services

11.59 Although in the minority of people diagnosed with AS/HFA, those who are within the forensic system "represent a highly unique population with specialised needs"[75].

11.60 The Reed Report (1992)[76] devoted a volume to the special needs of mentally disordered offenders with AS/HFA and the services required to meet those needs. The Scottish Executive Development Centre for Mental Health (2004)[77] has published an extensive document on the needs of people with Learning Disabilities and/or Autistic Spectrum Disorders in secure, forensic and other specialist settings. Recommendations common to both were that:

11.61 Agencies should take account of the specialised and varying needs of offenders with autism, including the importance of co-operation between different services:

- such agencies should train their staff to recognise and, where possible, respond to the special challenges presented by people with autistic disorders; and
- research is required into meet the needs of autistic people who offend or have severe behavioural problems.

11.62 The National Autistic Society[78] made a series of recommendations including:

- changes to definitions in mental health legislation;
- early assessment of cases suspected of having an autistic spectrum disorder where the police have arrested an individual;
- a code of practice or guidelines on evidence-based intervention, including medication, for individuals with autistic spectrum disorders; and
- the introduction of an enforceable legal right to an independent advocate for all patients formally and informally detained.

11.63 There are substantial deficiencies in the provision of Forensic Services for individuals with autistic spectrum disorders in Northern Ireland. This reflects the low levels of forensic services and also the shortfall in the provision of adequate and appropriate services for adults with AS/HFA in the general population[79]. There is only a limited number of specialised units in the UK.

11.64 There should be individual assessment of the needs of forensic service users with AS/HFA and their carers, followed by combining the available resources in a flexible manner to address those needs. Those resources are likely to include staff with appropriate expertise in Forensic Services and in assessing and managing AS/HFA. Good communication, co-ordination and co-operation between service providers is essential.

Recommendations

154. The Regional Forensic Network should co-ordinate a programme of training for staff in the identification, assessment, treatment and care of people suffering from Asperger's Syndrome or High Functioning Autism (AS/HFA) in Forensic Mental Health and Learning Disability Services and the Criminal Justice System.

155. The DHSSPS in partnership with Criminal Justice Agencies should commission a regional needs assessment to ascertain the prevalence of AS/HFA within the Criminal Justice and Forensic Services in Northern Ireland and to assess the needs of users and carers.

156. The DHSSPS should promote research into AS/HFA, including its relationship with offending behaviour, the effectiveness of specific psychological and environmental interventions, the development of models of service models and the definition of acceptable outcomes.

SERVICES FOR WOMEN

11.65 The Criminal Justice System and mental health and learning disability services must be gender sensitive and recognise the specific needs of both male and female service users. People who are subject to the Criminal Justice System and the users of forensic mental health and learning disability services are predominantly male and thus there are particular dangers that the specific needs of women are not adequately addressed.

11.66 The Department of Health in England reviewed many issues relating to women’s mental health[80]. As regards women offenders it was noted that:

- men commit more crime than women; less than 5% of the prison population are women;
- men start their criminal careers at an earlier age than women and are more likely than women to have lengthy criminal careers;
- women are more likely than men to commit acquisitive offences and are less likely to commit arson, violent or sexual offences;
- women are more likely than men to say that financial hardship, particularly in relation to their children, contributed to their crime;
- there has been a recent dramatic rise in the number of women in prison compared to men; and
- women in prison have experience of high levels of violence and abuse as children and as adults.

11.67 Women prisoners are:

- twice as likely as men to have received help for a mental/emotional problem in the 12 months before entering prison;
- less likely than men to receive a diagnosis of antisocial personality disorder and more likely to receive a diagnosis of borderline personality disorder;

- more likely to have severe mental illness;
- twice as likely as men to have symptoms associated with post-traumatic stress disorder; and
- more likely than men to have a history of self harm.

11.68 The Department recommended that the following principles should apply across all service settings:

- access to a same sex member of staff;
- access to a female doctor for physical healthcare;
- physical examinations to be undertaken by a female member of staff or with a female chaperone present;
- a female member of staff present if restraint is used;
- access to women-only therapy groups, particularly for issues such as violence and abuse;
- access to women-only social activities; and
- acknowledgement of caring responsibilities, for example through provision of childcare facilities, transport and flexible appointment times.

11.69 It also advocated the provision of single-sex forensic units, predominantly at medium and low security. In addition it recommended training for mental health practitioners on gender-related issues.

11.70 In England, a number of separate women's secure services have been developed. In Scotland it has been proposed that comprehensive Forensic Psychiatry Services forWomen should be provided in each of the 4 regional groupings that would meet all the treatment needs of women service users. These services would comprise dedicated multi-disciplinary teams with access to secure beds and easy progression to non-secure inpatient facilities or community services.

11.71 In Northern Ireland, there are no dedicated forensic mental health and learning disability services for women. The transfer of female prisoners from Mourne House, Maghaberry to Ash House at Hydebank Wood in June 2004 has been criticised [81]. An inspection of facilities at Ash House in November 2004 led to recommendations for a policy and strategic plan for the treatment of women in custody based on a full assessment of their specific needs. A separate prison was recommended for women in Northern Ireland and also the development of separate policies specific to women, the provision of therapeutic responses to self-harm and increased constructive activity. McClelland and colleagues (2005)[13] praised improvements in the services for women in Ash House. A full health needs assessment of the women in Ash House was completed in 2005.

11.72 At the time of writing this Report there are not known to be any women from Northern Ireland who are receiving treatment in high secure inpatient facilities, either in Northern Ireland or in other parts of the UK. Shannon Clinic provides accommodation that may be used by women and is partly separate from the facilities used by men, but with access to shared activities and rehabilitation facilities. There are no separate community forensic mental health and learning disability services for women.

DISCUSSION

11.73 The Criminal Justice System and mental health and learning disability services must be gender sensitive and recognise the specific needs and preferences of both male and female service users.

11.74 Several facilities for female forensic service users from Northern Ireland provide substantial or significant separation from male service users – the prison, Carstairs and Shannon Clinic.

11.75 There is a need to work closely with female service users and their advocates and carers to gain greater understanding of their needs and preferences and to develop and deliver services that are sensitive to and that respect these needs and wishes. It is particularly important to be clear about the reasons to either separate or integrate male and female service users. For example, much of the therapeutic work to address the effects of sexual abuse and trauma may be better carried out in a single sex environment. In other situations an integrated environment may facilitate work on social skills. Policies on these issues should be developed in all forensic services.

11.76 The relatively small numbers of women forensic service users may limit the range of facilities that can realistically be made available locally. In other regions it has been suggested that services should be combined, for example, at low and medium levels of security. There may also be benefit in providing services jointly with other service providers, for example, with Scotland or the Republic of Ireland.

11.77 Women forensic service users from Northern Ireland can generally receive assessment and treatment in a single sex environment in Carstairs and in the prisons. Shannon Clinic offers a degree of separation, combined with opportunities for integration. The assessment of the future needs for secure provision may well indicate that a separate low secure facility is more appropriate to the needs of women service users.

11.78 The Review has considered the provision of a separate community forensic service for women service users. Current needs would probably require a regional service to meet the needs of women service users. The Review considers that the individual needs of service users, both male and female, should be met by local community forensic services and that all such services should be gender sensitive.

11.79 Training should be provided for all staff in Forensic Services to ensure gender sensitivity.

Recommendations

157. Service commissioners and providers must ensure that services are gender sensitive. Planning and development of forensic services must take account of the needs and wishes of service users, their advocates and carers.

158. The Regional Forensic Network should co-ordinate the development of gender sensitive policies in all forensic services.

159. The proposed assessment of needs for secure provision (Chapter 8) should consider options to meet the needs of service users in a manner that is gender sensitive. This should include consideration of whether a separate low secure facility is more appropriate to the needs of women service users than the current provision in Shannon Clinic.

160. Community services should be provided individually to male and female users on the basis of individual needs and must be gender sensitive.

161. Service providers must ensure that staff in all Forensic Services receive training to ensure that services are gender sensitive.

FORENSIC PSYCHOTHERAPY

11.80 In order to provide comprehensive assessment, treatment and care, Forensic Services should take account of biological, psychological and social factors. Psychotherapy Services are particularly poorly developed at present and require specific consideration because of their fundamental importance in understanding and responding appropriately to the problems and needs of service users and their carers. There is a need to develop knowledge and skills in many areas of psychotherapy such as group analytic, family, systemic and individual psychoanalytical and cognitive behavioural approaches. Knowledge of the following should be developed:

- understanding the need for psychotherapeutic intervention as an important element in the treatment of psychosis and chronic mental disorders, including personality disorder, particularly where service users are in an institution or receiving other treatment and care for a long period of time;

- developing an understanding of the nature of personality disorder, particularly when there is a history of antisocial and criminal activity;

- awareness of the importance of personality disorder in service users with a diagnosis of major mental illness who have committed criminal acts;

- developing an understanding of the effects of psychopathology on abnormal and criminal behaviours, particularly aggression and sexual violence;

- understanding of group and institutional processes and the dynamics of the institutions involved in forensic settings including prisons and secure inpatient facilities;

- recognition of the personal impact of working with forensic service users and thus moderating the potential for a negative impact on clinical practice, management and multi-disciplinary working;

- recognition of the impact of offending and abusive experiences on service users, their victims and the institutions in which they are housed;

- understanding of criminological issues, including ethnicity, gender and culture; and

- aiding risk assessment and management by understanding the meaning of criminal activity to service users.

11.81 Forensic Psychotherapists require a wide range of skills including the following:

- expertise in assessment for Psychotherapy;
- expertise in one or more branches of Psychotherapy and knowledge of other branches of Psychotherapy, including the indications and contraindications in order to match therapy to the needs of service users;
- expertise in the use of security as part of treatment;
- understanding of the nature of risk and dangerousness and risk management, including appropriate communication with professional colleagues;
- expertise in the rehabilitation of service users who present potential risk to others;
- the ability to formulate problems from a systemic and organisational viewpoint, including understanding the effect of particular behaviours and teams and systems;
- expertise in clinical supervision;
- ability to evaluate the outcome of therapies; and
- the ability to formulate and communicate opinions clearly.

11.82 The Review recommends development of a range of multi-disciplinary therapeutic services that are integrated within Forensic Services. All staff working in Forensic Services should aim to develop high levels of knowledge and skill. They should be supported by specialist practitioners who have developed further knowledge and skills of psychotherapeutic practices and they should have strong links with psychotherapy departments.

11.83 Psychotherapeutic services should be provided to a broad range of forensic settings including high, medium and low secure inpatient facilities, prisons, community and outpatient facilities including therapeutic communities, hostels and community offender programmes.

11.84 Chapter 6 has noted the need for the DHSSPS to take the lead, in partnership with Criminal Justice Agencies to form a multi-agency consortium to promote psychotherapeutic expertise in the assessment and management of behavioural disturbance, personality disorder and offending behaviour.

Recommendations

162. The DHSSPS, the Regional Forensic Network, service commissioners and providers must ensure that planning and development of all inpatient and community mental health and learning disability forensic services incorporate and integrate a range of multi-disciplinary psychotherapeutic approaches.

163. All clinical staff working in forensic services must be provided with the appropriate opportunities and support to develop high levels of psychotherapeutic knowledge and skill.

164. The planning and delivery of forensic services must also include the provision of services by specialist Psychotherapists and Forensic Psychotherapists.

165. The DHSSPS must ensure that development and maintenance of forensic mental health and learning disability inpatient and community services is supported by robust workforce planning that takes account of the need to recruit and retain specialist Psychotherapists and Forensic Psychotherapists and to provide supervision, support and training to staff working in forensic services.

CHAPTER 12

IMPLEMENTING CHANGE

CO-ORDINATING DEVELOPMENTS AT REGIONAL AND LOCAL LEVELS – A REGIONAL FORENSIC NETWORK

12.1 Forensic Services in Northern Ireland must be developed to meet the needs of service users and carers at a local level and they must be co-ordinated across the region. The Review does not propose a fully detailed and prescriptive plan, but rather it advocates a process that is dynamic and interactive and which co-ordinates planning and development in an ongoing and strategic manner. It is proposed that Forensic Services should develop through partnerships between a regional co-ordinating group which sets the overall directions, priorities and sequence of change and local groups which implement change and ensure its integration with related services.

12.2 In recent years a number of organisational structures referred to as Managed Clinical Networks[82] have been developed to address problems similar to those faced by Forensic Services in Northern Ireland. These networks are regional or national organisations that bring together the key stakeholders to work in partnership to promote service development. Examples include the Northern Ireland Cancer Network and the Scottish Forensic Mental Health Services Managed Care Network.

12.3 In Scotland the national development of Forensic Mental Health Services is co-ordinated by a Managed Care Network Advisory Board which is chaired by the Head of the Mental Health Division in the Health Department. The Board comprises representatives from all the key organisations and provides dedicated time to its Chief Executive and Lead Clinician. The Advisory Board relates to the State Hospital and 4 regional groups which in turn relate to local services. The Board has commissioned a number of working groups to produce regional guidance and is developing regional multi-agency structures with links to NHS Regional Planning Groups. Thus the Scottish Network is an organisation with representation from the key stakeholders and with the capacity to co-ordinate functions at national, regional and local level.

12.4 The Review considers that a Northern Ireland Forensic Services Managed Network would be a logical development to advance the development of Forensic Services in Northern Ireland in accordance with the principles espoused by this Review. This Network would not only link together the developing services in Northern Ireland, but it could also establish useful connections with other developing forensic services in the rest of the United Kingdom, Ireland and further afield. Such external connections could, for example, lead to the sharing of service plans, experiences of service delivery and also staff training and development.

PURPOSES OF THE REGIONAL FORENSIC NETWORK

12.5 It is envisaged that the Forensic Services Managed Network (the Network) would have the following purposes:

> to plan, implement and evaluate the development and delivery of co-ordinated statutory and independent mental health and learning disability services for mentally disordered offenders and those with similar needs and to contribute to the prevention of mental disorder and associated harm.

12.6 It is considered essential that the remit of the Network should not focus narrowly or exclusively on the development and delivery of specialised Forensic Services. Instead it should be explicitly acknowledged that many service users with forensic needs currently have those needs met by a range of interconnecting services in primary and secondary care. There is a need both to support and develop these interconnecting services and at the same time to develop specialised forensic services. The Network should actively pursue both purposes in order to increase the capacity to meet needs and to enhance the quality of the services that are delivered.

THE REGIONAL FORENSIC NETWORK BOARD

12.7 The Network Board (the Board) should have appropriate accountability to Government and authority to resolve conflicts where these arise. The membership of the Board should comprise relevant commissioners and providers of mental health and learning disability services, representatives of service users and carers and associated organisations such as the Probation Board, the Police Service, the Prison Service, Housing and the Courts. The Board should include user and carer representation. Consideration should also be given to developing links with other developing forensic services outside Northern Ireland.

12.8 The functions of the Board should include:

- strategic planning;
- promoting and co-ordinating the development of systems to assess need and gather the information and evidence required for service planning;
- promotion of values and principles;
- promotion and development of comprehensive interconnected services;
- overseeing the development of co-ordinated systems of risk assessment and management;
- overseeing the development of quality assurance mechanisms that include setting and auditing standards and assessing the performance and quality of services;
- co-ordinating contributions to mental health promotion and education;
- co-ordinating developments in information systems and promoting research and innovation; advising the DHSSPS on recruitment and retention;

- promoting a co-ordinated approach to learning and development; and
- advising the DHSSPS on funding requirements.

12.9 The Board will require resources such as a Chair and Project Manager to carry out its tasks.

12.10 The Review envisages that the Regional Forensic Network will be part of the regional mental health and learning disability implementation process chaired by a Regional Director. In view of factors such as the specialised nature of the services, the potential high costs of some elements and the need to provide equity, the Review strongly favours the regional commissioning of forensic services.

Recommendations

166. The Review recommends the establishment of a Regional Forensic Network to co-ordinate the planning and delivery of Forensic Services at regional and local levels.

167. Forensic Services should be commissioned on a regional basis.

DEVELOPING CO-ORDINATED FORENSIC SERVICES

12.11 Although this Report has considered in separate chapters the services that should be delivered at different locations, it is essential that services are developed in a co-ordinated manner. Staff must work across locations in a manner that best meets the needs of service users and carers and supports the development of therapeutic relationships and continuity of care. For example, some staff will work both in inpatient settings and in community services; community forensic teams may provide in-reach forensic services to prisoners including preparation for return to the community and support following discharge from prison. As services grow and develop their structures will change, for example, it is proposed that community forensic learning disability services should begin as a regional service and then, following further assessment of needs and as resources become available, services should become more locally based and more closely integrated with other local services. Staff must work flexibly and co-operatively to support the growth and differentiation of services. At times staff will need to come together to learn from each other, to share information and resources such as protocols and training. At times there will be a need to pool all the relevant and available expertise, for example, in the assessment and management of particularly problematic or difficult cases. Forensic Services will also need to develop in an open manner, recognising and supporting the invaluable work of many other services in supporting mentally disordered offenders. Services must share information on service performance and quality and they must not become fragmented or isolated because of the high risks that can develop in those situations. Forensic services should also contribute to wider developments in the HPSS and in the Criminal Justice System.

12.12 Forensic Services in Northern Ireland are at the start-up of a process that will continue to evolve over many years. At this early stage, even though there is a great lack of information about the detailed needs of service users and their carers, there is an obvious and compelling case to urgently provide a number of components of a regional forensic service, as has been recommended in this Report. These initial developments should not be delayed by procedures to assess the needs, but nor should these initial developments distract from the underlying requirement to assess and monitor need and service performance. Thus the first phase of developing forensic services must include both the initial development of services and the detailed assessment of needs. After this initial phase, further developments must increasingly take account of assessed need and service performance. Services should continue to be developed to meet the needs, however, Forensic Services should not expand indefinitely and unthinkingly. Research must be conducted into the routes whereby individuals become mentally disordered offenders or forensic service users. Where possible, preventive measures should be introduced that help promote mental health and wellbeing. If our society is to address the challenges posed by mentally disordered offenders it must invest in the necessary long-term research and preventive strategies.

12.13 Thus the Review envisages an iterative process of development of Forensic Services, driven by assessed need, guided by principles and values, delivering quality-assured services to meet the needs and contributing through research to the reduction of need.

WORKFORCE PLANNING

12.14 The development of Forensic Services must be supported by effective workforce planning. This element is so fundamental to the successful development of services that its importance could hardly be overstated. A Workforce Strategy must be developed for Forensic Services that is similar to and co-ordinated with that for Adult Mental Health Services[83]. The workforce plan must address the recruitment and retention of staff in Forensic and interconnecting services.

12.15 There must also be learning and development strategies to provide staff with the necessary knowledge and skills. There must be arrangements for the training of new staff and the continuing professional development of existing staff. The training needs of staff working in Forensic Services and in interconnecting services must be analysed and training strategies devised to meet the needs. Users and carers should also be included in a comprehensive learning and development strategy, both to help in the training of staff and to meet their own needs. Training should be closely linked to the needs of the developing services. There are particular needs to provide training in psychotherapy and also psychotherapeutic support for staff who are working in this emotionally demanding field. Services should work together co-operatively to share training locally and regionally.

INFORMATION SYSTEMS

12.16 Similarly the Adult Mental Health Services Report[83] has identified the need for comprehensive and integrated information systems. The arrangements for information systems must extend across mental health and learning disability services encompassing Forensic Services and making the necessary links with the Criminal Justice System.

RESEARCH AND DEVELOPMENT

12.17 The development of Forensic Services must be supported by a Research and Development strategy. Priorities include:

- an assessment of needs to determine the numbers of people from Northern Ireland who require treatment in conditions of high, medium and low security and in community facilities should be commissioned by the DHSSPS. The assessment should include people suffering from mental illness, severe mental impairment and from personality disorder and other developmental disorders. It should encompass those who are currently receiving services and those who are currently unable for legal or other reasons to avail of such assessment, treatment and care;

- a detailed assessment of the needs of mentally disordered prisoners and their carers should be commissioned by the joint DHSSPS/NIPS project to transfer responsibility for prison healthcare to the NHS;

- an assessment should also be commissioned to examine the needs of service users who are placed in prison healthcare centres and the options for alternative services and placements;

- NIPS should commission research on the feasibility of reducing the number of people in prison by providing a broader range of facilities in the community, including lower security placements for mentally disordered women;

- research should also be commissioned to evaluate the methodology of assessing people in police stations and prisons with a view to ensuring the accurate identification of specified forms of mental disorder and need;

- epidemiological research should also be conducted into the needs of the population for forensic services;

- Research should also be incorporated into the developing services for offender therapy and personality disorder; and

- There are a number of clinical conditions that are poorly recognised or understood that require research priority such as AS/HFA and Attention Deficit Hyperactivity Disorder (ADHD) in adulthood.

THE PROCESSES OF CHANGE

12.18 The following outline sequence for the implementation of its recommendations proposes:

YEAR 1

12.19 The Regional Forensic Network should be established and its structures, resources, principles and purposes should be agreed. The Network should develop strategies for workforce planning, information systems and research.

12.20 An ongoing Workforce planning process should be developed for Forensic Services.

12.21 In Year 1 a detailed needs assessment should be commissioned to examine current and projected needs for high, medium and low security inpatient services and community facilities for people suffering from mental illness, learning disability and personality disorder and other developmental disorders. The results of this needs assessment should inform decisions on the needs for future services such as a high security service, additional medium secure places (particularly for longer stay), the numbers of new low secure places and the number and range of community facilities.

12.22 In addition the DHSSPS should examine the current obstacles to high secure care that are experienced by unsentenced prisoners and certain others and it should decide its strategy to resolve this highly unsatisfactory situation.

12.23 In Year 1 it is expected that responsibility for the healthcare of prisoners will transfer to the NHS. This will require agreement of the organisational structures and the range of services to be provided, and consideration of the assessed needs of prisoners including women and prisoners in healthcare centres.

12.24 A prison mental health promotion group should be established and also a consortium to provide therapies for offenders.

12.25 The Community Forensic Services should be developed further and a regional forensic learning disability service should be initiated.

12.26 Work should commence on developing an interagency framework for the assessment and management of risk.

YEAR 2

12.27 Further needs assessment should be commissioned to establish the needs of the population for Forensic Services. The assessments should also include specific examination of the needs of mentally disordered people in police stations, on bail, at court and on probation and the needs of their carers.

12.28 A strategy should be agreed on the future profile and development of high, medium and low secure provision and related community facilities.

12.29 Proposals should be published on an interagency risk framework.

12.30 Work should begin to develop regional guidance on fitness for interview , fitness to attend court, and to review the appropriate adult scheme.

12.31 The Regional Forensic Network should agree quality standards for mental health and learning disability services to people in the Criminal Justice System and for forensic inpatient and community services.

12.32 Health promotion opportunities should be identified in the Criminal Justice System and for forensic inpatient and community services.

YEAR 3

12.33 Commissioners should use the results of the needs assessments to commission a full range of mental health and learning disability services to people in police stations and also local Community Forensic Learning Disability Teams.

12.34 Five CFT's should be resourced and fully operational.

12.35 A regional strategy should be agreed on the future assessment, treatment and care of people with personality disorder.

12.36 Psychotherapy services should be fully integrated within inpatient and community forensic services.

12.37 The regional body with responsibility for quality assurance should agree quality standards for mental health and learning disability services to people in the Criminal Justice System and for forensic inpatient and community services.

12.38 A health promotion strategy should be agreed and implemented for the Criminal Justice System and for forensic inpatient and community services.

YEAR 5

12.39 Further assessment should be undertaken of the needs of the population for Forensic Services, including examination of the needs of people in the Criminal Justice System and forensic inpatient and community services.

12.40 A comprehensive offender therapy consortium should be in place.

12.41 Regional guidance should be completed.

YEAR 7

12.42 Low secure services should be in place to meet the assessed needs.

YEAR 10

12.43 Further assessment should be undertaken of the needs of the population, including people in the Criminal Justice System and forensic inpatient and community services.

12.44 Additional high secure and medium secure places should be provided to meet the needs.

PERFORMANCE INDICATORS

12.45 The following tables provide further details of the performance indicators, targets, milestones, responsibilities and the sources of information that will confirm implementation:

1. Regional Planning and Co-Ordination to Include Service Users and Car ers

Performance Indicators	Targets	Milestones	Lead Responsibility	Information & Sources
Regional Forensic Network to be established and to include user & carer representatives	Network established User & carer representatives appointed	Year 1 Year 1	DHSSPS	Network structures, values, principles and plans
DHSSPS & NIPS to agree organisational structures in prisons, to include user & carer representatives	Structures agreed User & carer representatives appointed	Year 1 Year 1	Transfer project	DHSSPS & NIPS

2. Assessment and Monitoring of the Needs of Service Users and Car ers

Performance Indicators	Targets	Milestones	Lead Responsibility	Information & Sources
Assessment of the needs of prisoners, including the needs of carers, women and prisoners in healthcare centres	Information for service planning and funding Information on need and service impact, to aid service planning	Year 1 Repeat at years 5 & 10	NIPS/DHSSPS transfer project	Transfer Project Local Service Providers
Assessment of the needs of people in police stations, on bail, at court and on probation	Information for service planning Information on need and service impact, to aid service planning	Year 2 Repeat at years 5 & 10	DHSSPS	DHSSPS
Assessment of needs for high, medium & low security & community placements for short, medium and long stay for people with mental illness & learning disability	Information for service planning Information on need and service impact, to aid service planning	Year 1 Repeat at years 5 & 10	DHSSPS	DHSSPS
Assessment of needs for secure & community placement for people with personality disorder & other developmental disorders	Information for service planning Information on need and service impact, to aid service planning	Year 2 Repeat at years 5 & 10	DHSSPS	DHSSPS
Service information from Community Forensic Services & Regional Secure Unit	Information for service planning	Annual	Local Service Providers	Local Service Providers

3. Effective Mental Health and Learning Disability Services for People Subject to the Criminal Justice System

Performance Indicators	Targets	Milestones	Lead Responsibility	Information & Sources
Full range of mental health and learning disability services arranged for prisoners	All services in place before transfer of responsibility in April 2007	Year 1	Transfer project	Information published by Transfer project
Commissioners to commission a full range of mental health & learning disability services to people in police stations, on bail, at court and on probation	Completed following needs assessment	Year 3	DHSSPS	DHSSPS
Service providers to provide a full range of mental health & learning disability services to people in police stations, on bail, at court and on probation	Protocols and services in place to provide access to full range of services	Year 5	Local Service Providers	Local Service Providers
Development of an offender therapy consortium	Basic structure established Resource needs agreed Comprehensive services in place	Year 1 Year 2 Year 5	DHSSPS	DHSSPS
Regional guidance on fitness for interview, fitness to attend court, review of appropriate adult scheme etc	Group(s) formed All work completed	Year 2 Year 5	DHSSPS	Regional guidance issued and appropriate training & resources provided

4. Effective Inpatient and Community Forensic Mental Health and Learning Disability Services

Performance Indicators	Targets	Milestones	Lead Responsibility	Information & Sources
Review of options and formulation of strategy for high security provision	High secure services must be available to all people in N Ireland who require them. Follows needs assessment in Year 1	Year 2	DHSSPS	DHSSPS
Strategy for high, medium & low security & community placements for short, medium and long stay for people with mental illness & learning disability	Full range of places must be available to meet needs Strategy follows needs assessment in Year 1 Provision of low secure and community facilities Provision of high security and long stay medium security	Year 2 Year 7 Year 10	DHSSPS	DHSSPS
Development of community forensic teams Initial development Further development	5 fully operational teams Further developments following service information and needs assessment	Year 3 Year 7	DHSSPS	DHSSPS
Development of a regional forensic learning disability service	Regional inpatient and community service	Year 1	DHSSPS	DHSSPS

4. Effective Inpatient and Community Forensic Mental Health and Learning Disability Services

Performance Indicators	Targets	Milestones	Lead Responsibility	Information & Sources
Development of local forensic learning disability teams	5 local teams	Year 3	DHSSPS	DHSSPS
Services for people with personality disorder	Needs assessment	Regional strategy	Year 2	Year 3
Psychotherapy services	A full range of psychotherapy services fully integrated within all inpatient & community forensic services	Year 3		

5. Assessing and, Where Possible, Minimising the Risks of Harm that are Associated with Mental Disorder

Performance Indicators	Targets	Milestones	Lead Responsibility	Information & Sources
DHSSPS & NIO to develop a risk assessment and management framework	Group constituted Proposals published Framework implemented	Year 1 Year 2 Year 3	DHSSPS	DHSSPS
Inpatient and community forensic services to develop risk assessment and management policies, procedures and protocols	Policies, procedures and protocols in place. Regular updates	Year 1	Regional Forensic Network	Regional Forensic Network

6. Continuing Quality Improvement

Performance Indicators	Targets	Milestones	Lead Responsibility	Information & Sources
DHSSPS & NIPS to agree clinical governance and internal quality assurance mechanisms for prisons	Clinical governance and internal quality assurance mechanisms agreed and implemented before transfer	Year 1	Transfer Project	Transfer Project
Clinical governance and internal quality assurance mechanisms to be agreed for inpatient & community forensic services	Clinical governance and internal quality assurance mechanisms agreed	Year 1	Local Service Providers	Local Service Providers
Development of regional standards for mental health and learning disability services to the criminal justice system and for forensic inpatient & community services	Standards agreed Year 2	Regional Forensic Network	Regional Forensic Network	
Regional quality assurance body to develop quality standards for mental health and learning disability services to the criminal justice system and for forensic inpatient & community services	Quality standards agreed	Year 3	RQIA Regulation and Quality Improvement Authority	RQIA Regulation and Quality Improvement Authority

7. Promoting Mental Health

Performance Indicators	Targets	Milestones	Lead Responsibility	Information & Sources
Establish a regional prison mental health promotion group	Agree and implement strategy before transfer of responsibility	Year 1	Transfer project	Transfer project
Identify opportunities for mental health promotion for people in police stations, on bail, in court and on probation	Assess opportunities Agree and implement strategy	Year 2 Year 3	DHSSPS	DHSSPS
Identify opportunities for mental health promotion for people in inpatient & community forensic services	Assess opportunities Agree and implement strategy	Year 2 Year 3	Regional Forensic Network	Regional Forensic Network

8. Meeting the Information Needs of Service Users, Carers and Service Providers

Performance Indicators	Targets	Milestones	Lead Responsibility	Information & Sources
Healthcare information systems to be established in prisons to meet the needs of mentally disordered prisoners	Completed before transfer of responsibility	Year 1	Transfer project	Transfer project
HPSS information systems should extend to people in police stations and courts	Appropriate HPSS information accessible to healthcare staff working in the Criminal Justice System	Year 3	DHSSPS	DHSSPS
Promoting communication with all relevant parties	Forensic inpatient & community services to develop information strategies	Year 2	Regional Forensic Network	Regional Forensic Network
Promoting research	Forensic inpatient & community services to develop research strategies	Year 2	Regional Forensic Network	Regional Forensic Network

9. Delivering an Effective, Competent and Confident Workforce

Performance Indicators	Targets	Milestones	Lead Responsibility	Information & Sources
A comprehensive workforce strategy for forensic services	Agreed strategy	Year 1	DHSSPS	DHSSPS
A strategy for workforce recruitment	Strategy implementation targets to be agreed	To be agreed	DHSSPS	DHSSPS
A strategy for training needs analysis and workforce training	Agreed strategy	To be agreed	DHSSPS	DHSSPS
A strategy for training in psychotherapies	Agreed strategy for training in psychotherapies	Year 1	DHSSPS	DHSSPS

Recommendations

1. A Regional Forensic Network should co-ordinate and lead the strategic planning of forensic services in Northern Ireland.

2. Strategic planning must be guided by evidence and by values and principles. The Regional Forensic Network must establish systems of gathering the necessary information and evidence to inform the further development of services.

3. The Regional Forensic Network should establish explicit values and principles to guide the planning and development of forensic services. The values and principles adopted by this Review (see 2.3-2.5) are recommended. In addition the following principles are recommended for forensic services:

   i. there should be joint co-operative planning between the Criminal Justice Agencies and the Health and Personal Social Services and joint delivery of services in order to best meet the needs of service users and carers;

   Mentally disordered offenders and others with similar needs should receive treatment, care and support for their mental disorder that is:

   ii. as far as possible in the community, rather than in inpatient settings;

   iii. under conditions of security and restriction no greater than as is justified by the degree of danger they present to themselves or others; and

   iv. open, accountable and subject to external review.

4. The planning and development of forensic services should take full account of the 10 Standards identified in this Report.

5. Service commissioners must commission a full range of statutory mental health and learning disability services to meet the needs of mentally disordered people detained in police stations.

6. Providers of statutory, voluntary and community mental health and learning disability services must ensure they provide equity of access and provision of services for people detained in police stations.

7. Mental health and learning disability services to people detained in police stations should be provided locally and co-ordinated regionally. The Department of Health, Social Services and Public Safety (DHSSPS) should lead this co-ordination in liaison with the Regional Forensic Network.

8. Research should be commissioned to assess the needs of mentally disordered people and their carers in police stations throughout Northern Ireland. This research should include recommendations leading to the establishment of systems to monitor ongoing need and the impact of services on need.

9. Advocacy services associated with community mental health and learning disability services should be extended to include police stations.

10. Clear organisational structures, accountability and governance arrangements must be agreed for mental health and learning disability services to police stations.

11. Service providers should develop information systems that enable FM0s and staff working in mental health and learning disability services to gain appropriate access to the health records of people detained in police stations.

12. Research should be commissioned to evaluate the methodology of assessing suspects in police stations with a view to ensuring the accurate identification of specified forms of mental disorder and need.

13. The DHSSPS in partnership with Criminal Justice Agencies should establish a group comprising relevant stakeholders to produce guidance on assessment of fitness for interview and related matters.

14. The DHSSPS in partnership with Criminal Justice Agencies should establish a group comprising representatives of all the relevant stakeholders to review the appropriate adult scheme. The group should consider the effectiveness, efficiency and practical working of the scheme, including the criteria invoking the use of appropriate adults.

15. Commissioners should commission services for the safe assessment, treatment and care of mentally disordered offenders in police stations.

16. Service providers and other stakeholders should agree joint protocols for the assessment and management of mentally disordered people in police stations, including those whose behaviour is disturbed.

17. Commissioners should commission services that provide police with ready access to advice from suitably qualified health professionals.

18. The DHSSPS in partnership with Criminal Justice Agencies should establish a group comprising relevant stakeholders to develop a risk assessment and management framework that extends across the Criminal Justice System and the HPSS and that applies to mentally disordered people in police stations.

19. The relevant regional body with responsibility for assuring the quality of mental health and learning disability services must ensure that quality standards are developed for mental health and learning disability services in police stations and that services are audited and subject to external independent inspection.

20. Service commissioners and providers should liaise with the regional body with responsibility for mental health promotion to identify opportunities for mental health promotion within police stations and ensure that appropriate services are provided and their impact evaluated.

21. The DHSSPS should ensure that research programmes are commissioned to examine the efficacy of different models of services to mentally disordered offenders in police stations with a view to informing further service planning.

22. The DHSSPS should ensure that development of Information Systems within the HPSS takes account of the need to provide health and social services to people in police stations.

23. The DHSSPS in partnership with Criminal Justice Agencies should ensure that an assessment is undertaken of the learning and development needs of stakeholders including police, FMO's, lawyers and health and social services staff.

24. Appropriate training strategies should be devised and implemented to meet the identified needs for both induction training and for continuing professional development.

25. The development and maintenance of services for mentally disordered people in police stations across the province requires appropriate funding from the relevant sources. Funding should be delivered in accordance with a long term plan that ensures sustainable development of services. Funding arrangements must support the joint co-ordinated planning and delivery of services. There must be mechanisms that demonstrate that monies made available to services have reached their intended targets.

26. The Northern Ireland Prison Service (NIPS) should commission research on the feasibility of reducing the number of mentally disordered people in prison by providing a broader range of facilities in the community. The research should address the mental health and social needs of male and female remand prisoners as well as the requirements of the Criminal Justice System. It should consider the potential utility of facilities with joint input by criminal justice staff and health and social services staff to offer different levels of supervision and therapy for a wide range of mental disorders including mental illness, learning disability, personality disorders and alcohol and substance misuse.

27. Service commissioners should commission a full range of statutory, voluntary and community mental health and learning disability services to meet the needs of mentally disordered people attending courts.

28. Providers of community mental health and learning disability services should ensure they provide equality of access and provision of services for people attending courts.

29. In Year 5, when forensic mental health and learning disability services in Northern Ireland have increased in size and capacity, a detailed option appraisal should be undertaken to consider the provision of assessments and other services for the courts by alternative means, including by service level agreements.

30. The DHSSPS in partnership with Criminal Justice Agencies should establish a group of relevant stakeholders to produce guidance on the assessment of fitness to attend court.

31. Service providers must ensure that healthcare staff assessing and treating prisoners attending court have ready and appropriate access to existing healthcare information

32. The DHSSPS should establish a group with the Court Service and other relevant stakeholders to review and develop procedures and protocols in relation to mentally disordered offenders to ensure efficient and effective operation.

33. The relevant regional body with responsibility for assuring the quality of mental health and learning disability services should ensure that quality standards are developed for mental health and learning disability services in courts and that services are audited and subject to external independent inspection.

34. Service commissioners and providers should liaise with the regional body with responsibility for mental health promotion to identify opportunities for mental health promotion at courts and ensure that appropriate services are provided and their impact evaluated.

35. The DHSSPS in partnership with Criminal Justice Agencies should ensure that an assessment is undertaken of the learning and development needs of stakeholders including court staff, lawyers, judiciary and health and social services staff.

36. Appropriate training strategies should be devised and implemented to meet the identified needs for both induction training and for continuing professional development.

37. The proposed review of options for mental health and learning disability services to the courts should include consideration of funding mechanisms.

38. Improvement of the mental health of prisoners requires a partnership between the DHSSPS and the NIPS to ensure:

    - development of a prison environment that actively promotes mental health and well-being; and
    - provision of a comprehensive range of mental health and learning disability services which address the needs of prisoners and are integrated with other community and prison services to ensure effective through care.

39. The Review welcomes the decision to transfer responsibility for the healthcare of prisoners to DHSSPS and emphasises that it must be supported by robust quality assurance mechanisms and by sufficient resources to meet the needs.

40. The Review recommends that planning the future of mental health and learning disability services for prisoners is integrated with the planning of mental health and learning disability services throughout Northern Ireland including the joint strategic approach co-ordinated by the Regional Forensic Network.

41. The joint DHSSPS/NIPS project to transfer responsibility must ensure that a detailed assessment of the needs of mentally disordered prisoners and their carers is completed by the end of 2006. The assessment of need must encompass all those suffering from mental disorder including mental illness, learning disability, personality disorder and alcohol and substance misuse. It must take full account of the resources required by health and social services staff to work co-operatively in support of criminal justice staff.

42. The needs assessment must lead to the provision for service commissioners of systems to monitor and evaluate in an ongoing manner the needs of service users and carers and the impact of services on need.

43. The DHSSPS and NIPS in partnership should develop explicit values and principles for mental health and learning disability services and Criminal Justice Services for prisoners that guide the development of a prison environment that actively promotes mental health and well-being and that provides a comprehensive range of mental health and learning disability services.

44. The DHSSPS and NIPS in partnership should agree arrangements to develop strong and cooperative working relationships between prison staff, health and social services staff, and Criminal Justice Agencies at operational and managerial levels. These should include the supporting organisational structures, training and the development of joint policies, protocols and procedures.

45. Commissioners of mental health and learning disability services in prisons must ensure that service users and carers are involved in the development, delivery and monitoring of services.

46. Commissioners of mental health and learning disability services in prisons must ensure that advocacy services and complaints procedures are developed for service users in prisons, building on those already in place.

47. The project overseeing the transfer of lead responsibility must ensure that joint working arrangements with all relevant mental health and learning disability service providers are agreed and published before April 2007. It must be demonstrated that service providers have sufficient resources and capacity to meet the identified needs, including the needs of prisoners and discharged prisoners who are suffering from mental illness, learning disability, personality disorder and alcohol and substance misuse. The arrangements must take full account of the resources required by health and social services staff to work co-operatively in support of criminal justice staff in relation to prisoners and discharged prisoners.

48. The Review supports the recommendations made by Professor McClelland and colleagues (2005) in relation to the assessment, treatment and care of prisoners on committal to prison. The transfer project should ensure that work continues as quickly as possible to address these recommendations and that arrangements are made to complete any outstanding work following transfer of responsibility.

49. Commissioners of mental health and learning disability services for prisoners must ensure that services provide assessment, treatment and care for all people suffering from mental disorder including those suffering from personality disorder.

50. DHSSPS should take the lead in developing, in partnership with the Criminal Justice Agencies, an inclusive model of assessment, treatment and care of people suffering from personality disorder.

51. A specific mental health needs assessment should be commissioned as part of the programme of the transfer of lead responsibility to examine the needs of service users who are placed in prison healthcare centres and the options for alternative services and placements. This should be completed by the end of 2006.

52. Services should be commissioned for women prisoners that are gender sensitive and that have the capacity to respond appropriately to the range of their mental health and learning disability needs, including substance misuse and personality disorder.

53. NIPS should commission a research project into alternatives to prison for mentally disordered women, including placements at lower levels of security.

54. A full range of mental health and learning disability services including adolescent, psychotherapy and personality disorder, alcohol and substance misuse should be commissioned. Community service providers must ensure that a full range of co-ordinated services is developed and provided to those who are under the age of 18, and DHSSPS must play its part in ensuring adequate provision of the necessary expertise.

55. Service providers must develop protocols and procedures so that management plans are jointly agreed in the case of each adolescent suffering from mental disorder when transferring to adult prison services or healthcare services in the community.

56. The transfer project team should define requirements and, together with service commissioners and providers, put such arrangements in place before April 2007.

57. People who require admission to hospital for assessment or treatment under the provisions of the mental health legislation must have equal access and priority whether they originate in prison or in the community. The application of this standard in practice should be subject to external audit by the appropriate health care inspection body.

58. The transfer project should ensure that specific joint working arrangements between service providers, the Prison Service and the DHSSPS are agreed and published before April 2007.

59. The DHSSPS in partnership with Criminal Justice Agencies should establish a group comprising relevant stakeholders to develop a risk assessment and management framework that extends across the Criminal Justice System and the HPSS and that applies to mentally disordered people in prisons. The framework must not discriminate unjustifiably against people suffering from mental disorder.

60. Mental health and learning disability services and Criminal Justice Agencies should develop joint co-ordinated interagency standards that encompass both the creation of a prison environment that promotes mental health and the provision of a full range of mental health and learning disability services. These standards should be supported by clinical governance arrangements, internal quality assurance mechanisms, external independent inspection and systems of learning from adverse events. NIPS and DHSSPS should jointly set up an effective operational group in 2006.

61. The DHSSPS, involving the body with regional responsibility for mental health promotion, in partnership with NIPS, service providers and representatives of users and carers should establish a Regional Prison Mental Health Promotion group to address mental health promotion and suicide prevention. The group should build upon the existing policy and formulate a strategy that sets explicit standards. It should seek to establish a culture and ethos in the prisons that promotes mental health and well-being for prisoners and staff and that further reduces the risks of suicide. The goal should be for the initial strategy to be implemented by 2007. Work should continue in conjunction with the regional body with responsibility for mental health promotion and should include evaluation of its effects.

62. The transfer project should ensure that information systems are established before April 2007 to meet the needs of mentally disordered prisoners. Information systems for prisoners should integrate and evolve with the HPSS systems and should be developed, where appropriate, to integrate with criminal justice systems in support of joint working.

63. The DHSSPS should commission and promote ethically approved research in relation to the needs and services for mentally disordered prisoners, for example research should be undertaken into the needs for healthcare centre places, the transfer of prisoners to Health Service, bail and community step-down facilities, the efficacy of offender management programmes and the efficacy of mental health promotion strategies.

64. The DHSSPS must ensure that development and maintenance of services for mentally disordered prisoners are supported by robust workforce planning and provision of opportunities for staff to avail of learning, development and support.

65. Service providers must ensure that learning and development strategies for all staff are closely linked to service development and to governance arrangements.

66. A multi-agency consortium should be formed in 2006 to promote psychotherapeutic expertise in the assessment and management of behavioural disturbance, personality disorder and offending behaviour. The lead should be taken by DHSSPS with input from criminal justice agencies and the relevant health sector bodies.

67. The strategic development of mental health and learning disability services for prisoners requires sustainable additional funding. Funding arrangements must support the joint co-ordinated multi-agency planning and delivery of services. There must be mechanisms that demonstrate that monies made available to services have reached their intended targets.

68. Strategies should be developed to ensure effective joint working between PBNI and the full range of mental health and learning disability services in relation to the assessment, treatment and care of mentally disordered people who are undergoing assessment by Probation or are subject to a Probation Order.

69. The Regional Forensic Network should co-ordinate the development of services at the interfaces between PBNI and:

- community forensic mental health and learning disability services;
- prison forensic services; and
- inpatient secure services.

70. The DHSSPS should, in partnership with PBNI, co-ordinate the development of services at the interfaces between PBNI and other mental health services.

71. PBNI, the Regional Forensic Network and the DHSSPS should agree joint arrangements to assess and monitor the needs of mentally disordered individuals, their carers, their representatives, service providers and the wider community. The results of ongoing assessment should inform service planning.

72. PBNI, the Regional Forensic Network and the DHSSPS should agree joint purposes, clear organisational structures and lines of accountability and should develop policies, protocols and procedures for joint working and information sharing.

73. PBNI, the Regional Forensic Network and the DHSSPS should develop comprehensive and accessible joint services to assess and provide treatment and care for mentally disordered people in contact with probation. There are particular needs to develop joint psychotherapeutic approaches.

74. The DHSSPS in partnership with Criminal Justice Agencies should establish a group comprising relevant stakeholders to develop a risk assessment and management framework that extends across the Criminal Justice System and the HPSS and that applies to mentally disordered people undergoing assessment by Probation or subject to a Probation Order.

75. PBNI, the Regional Forensic Network and the DHSSPS should agree standards for joint working. Services should be subject to internal and external evaluation of performance and quality.

76. PBNI and mental health and learning disability services should identify opportunities for mental health promotion and agree appropriate services.

77. Inter-agency learning and development arrangements should be established to support joint working between PBNI and forensic and other mental health and learning disability services.

78. The development of forensic and other mental health and learning disability services to support the work of PBNI requires sustainable funding from the relevant sources. Funding arrangements must support the joint co-ordinated planning and delivery of services. There should be mechanisms to demonstrate that monies made available to services have reached their intended targets.

79. The Regional Forensic Network should promote co-ordination of forensic service provision for the people of Northern Ireland, including with high security services at the State Hospital, Carstairs, Scotland.

80. The current arrangements for high secure services for people in Northern Ireland have unacceptable gaps in service provision. All people in Northern Ireland must have access to high secure services when they require them. The DHSSPS must take the lead in urgently finding solutions to the current obstacles to treatment and care in conditions of high security.

81. The DHSSPS must commission an assessment of needs to determine the numbers of people from Northern Ireland who require treatment in conditions of high and medium security. The assessment should include people suffering from mental illness, severe mental impairment and from personality disorder. It should encompass those who are currently receiving services and those who are currently unable for legal or other reasons to avail of such assessment, treatment and care.

82. This assessment of high and medium secure needs should be combined with an assessment of the needs for low secure and step-down community services (Chapter 9) and the needs for forensic learning disability services (Chapter 10).

83. The Review recommends the provision of an additional secure facility in Northern Ireland to meet the identified high and medium secure needs of service users. The regional high and medium secure facilities should be complemented by local low secure facilities and community step-down facilities to form a range of short, medium and longer stay facilities that meet the needs of forensic service users.

84. New secure services should be developed in accordance with the standards proposed by this Review.

85. The Regional Forensic Network should explore the range of opportunities to co-ordinate training for staff in Forensic Mental Health and Learning Disability Services in Northern Ireland with the training available in adjacent jurisdictions.

86. The Regional Forensic Network should promote the development and delivery of regional medium secure services and their co-ordination with interconnecting services.

87. The DHSSPS must take account of the assessment of need for secure services and it must plan and develop long stay medium secure services and step-down low secure and community services

88. In order to inform service planning and development Shannon Clinic staff should analyse the needs of each service user and the constraints on his or her progress.

89. The Regional Forensic Network should establish systems to monitor ongoing need for high, medium and low secure services and step-down community services for forensic service users with short, medium and longer stay needs. This information should contribute to the planning and delivery of forensic services.

90. Commissioners of mental health and learning disability services to the prisons should ensure that arrangements facilitate the early identification and transfer to hospital of mentally disordered people who require treatment in conditions of medium security .

91. Service providers should develop regional expertise at Shannon Clinic in the assessment and management of risk in relation to service users who require assessment, treatment and care in conditions of medium security.

92. Shannon Clinic should develop explicit quality standards and quality assurance mechanisms, including audit and independent external inspection by the relevant regional body.

93. The Regional Forensic Network should co-ordinate with the regional body with responsibility for mental health promotion to facilitate the contribution of secure inpatient services to mental health promotion and public education.

94. The Regional Forensic Network should develop information and research strategies and promote the involvement of secure inpatient services.

95. The Regional Forensic Network should promote the integration of InformationTechnology systems between medium secure services and interconnecting services to help ensure the effective transfer of information.

96. The model used by Shannon Clinic of closely integrating training with clinical practice should extended to other forensic services.

97. The DHSSPS must ensure that development and maintenance of secure inpatient services is supported by robust workforce planning and provision of opportunities for staff to avail of learning, development and support.

98. The development and maintenance of medium secure services requires appropriate funding in accordance with a long term plan that ensures sustainable development of services. There must be mechanisms that demonstrate that monies made available to services have reached their intended targets.

99. The DHSSPS should ensure the development and delivery of low secure forensic services including step-down rehabilitation and long-stay services.

100. The DHSSPS must commission an assessment of needs to determine the numbers of people from Northern Ireland who require treatment in conditions of low security The assessment should include people suffering from mental illness, severe mental impairment and from personality disorder. It should encompass those who are currently receiving services and those who are currently unable for legal or other reasons to avail of such assessment, treatment and care.

101. The needs assessment should consider the optimal configuration of low secure services, including the needs of specific groups such as women.

102. The needs assessment should lead to the development of low secure services that are fit for purpose. This is likely to require substantial new provision.

103. It is recommended that future low secure services, including low secure forensic services are developed in accordance with the standards advocated in Chapter 2.

104. The Regional Forensic Network should lead and co-ordinate the planning and development of community forensic services. It should both support and build upon the capabilities of current services as well as developing and integrating new specialist services.

105. The 5 CFT's that are currently partly staffed and funded require the necessary funding and workforce planning from the DHSSPS to ensure they are developed to full operational capacity by 2010. Thereafter teams should be developed in response to need to ensure that they have capacity to fulfill the range of services required by service commissioners and service users.

106. Commissioners must commission a full range of community forensic services with the following purposes:

- assessing local referrals to secure inpatient services;
- supporting the discharge of service users from inpatient secure services to the community, facilitating self management, opportunities for employment and engagement in social activities;
- working jointly with other mental health and learning disability services to provide consultation, assessment, and support and, in some cases, shared or sole treatment and care;
- liaison with police stations and courts;
- in-reach to prisons and support of discharged prisoners with mental disorder;
- assessments at the request of probation;
- input to offender therapy programmes; and
- supporting the work of the MASRAM or its successor.

107. The CFT's should produce information on their workload and performance which, combined with needs assessments should help guide the future planning of CFTs' including suitable accommodation in the community.

108. Community Forensic Services should develop specific service models and structures and agreed methods of working with interconnecting services.

109. A CFT should comprise a range of staff with the necessary skills to meet the needs of users and carers. The following is considered representative of the skills and funding levels required:

1	Consultant Forensic Psychiatrist
1	Consultant Chartered Forensic Psychologist
1	Forensic Psychologist
1	Psychotherapist
2	Social Workers
1	Occupational Therapist
5	Nurses
2	Administrative Staff
User and carer advocacy services	

The composition of CFTs should be adjusted in response to information on need and service performance.

110. The Regional Forensic Network should co-ordinate the development and delivery of community forensic services, including the development of policies, procedures and protocols.

111. The Regional Forensic Network should co-ordinate the development of risk assessment and management policies, procedures and protocols by community forensic services.

112. The Regional Forensic Network should promote and co-ordinate the development of performance and quality standards for community forensic services and ensure that there are robust quality assurance mechanisms including internal audit and independent external inspection and review.

113. The Regional Forensic Network should co-ordinate with the regional body with responsibility for mental health promotion to ensure that community forensic services contribute to mental health promotion and public education.

114. The Regional Forensic Network should co-ordinate the development of information and research strategies for community forensic services. It should promote the use of information technology to support and enhance multi-disciplinary and inter-agency communication and information-sharing, in accordance with agreed protocols.

115. The DHSSPS must ensure that development and maintenance of community forensic services is supported by robust workforce planning and provision of opportunities for staff to avail of learning, development and support.

116. The development of community forensic services requires additional sustainable funding from the relevant sources. Funding arrangements must support the joint co-ordinated planning and delivery of services. There should be mechanisms to demonstrate that monies made available to services have reached their intended targets.

117. The Regional Forensic Network should lead the development of forensic learning disability services in Northern Ireland, in co-ordination with the Learning Disability Implementation Group. Forensic Learning Disability Services should link with forensic services outside the province, including the State Hospital Carstairs and the Scottish Forensic Mental Health Services Managed Care Network. Co-ordinated services must be planned and developed to meet the short, medium and longer term needs of service users at high, medium and low levels of security.

118. The needs assessment and service mapping exercise advocated at 8.28 and 9.17 should include a detailed assessment of the needs for forensic learning disability services. This should lead to the development of a comprehensive plan and the development of a full range of inpatient and community forensic learning disability facilities and services. The Review advocates the provision of additional high and medium security services for people with learning disability in the proposed new unit (Recommendation 83). There is also a need for local low security services and community forensic learning disability services.

119. The forensic learning disability services in Northern Ireland are currently so patently inadequate that their initial development does not need to await the completion of a needs assessment exercise. A regional forensic learning disability service should be developed immediately which supports the further development of 5 localised and regionally co-ordinated teams.

120. Commissioners of mental health and learning disability services to the prisons should ensure that arrangements facilitate the early identification and transfer of people who require assessment, treatment and care in forensic learning disability inpatient services.

121. The DHSSPS must address the current obstacles to service users with learning disability receiving inpatient care, including uncertainty over the definition of the term “severe mental handicap” and the lack of step-down services at low security and in the community.

122. The Regional Forensic Network should promote the development of joint working policies, procedures and protocols between forensic learning disability services and interconnecting mental health and learning disability services and services in the Criminal Justice System.

123. The Regional Forensic Network should promote the development by forensic learning disability inpatient services of risk assessment and management polices, procedures and protocols that co-ordinate with mental health services and with the Criminal Justice System (see Chapter 11).

124. The Regional Forensic Network should co-ordinate the development of robust systems to assess performance and assure quality and clinical governance for forensic learning disability inpatient services.

125. The Regional Forensic Network should co-ordinate with the regional body with responsibility for mental health promotion to facilitate the contribution of secure forensic learning disability inpatient services to mental health promotion and public education.

126. The Regional Forensic Network should co-ordinate the development of information systems and research in forensic learning disability services.

127. The Regional Forensic Network should promote the integration of InformationTechnology systems between forensic learning disability services and interconnecting services to help ensure the effective transfer of information.

128. The DHSSPS must ensure that development and maintenance of forensic learning disability inpatient services is supported by robust workforce planning and provision of opportunities for staff to avail of learning, development and support.

129. The development and maintenance of forensic learning disability services requires appropriate funding from the relevant sources. Funding should be delivered in accordance with long-term plans that ensures sustainable development of services. Funding arrangements must support the joint co-ordinated planning and delivery of services. There must be mechanisms that demonstrate that monies made available to services have reached their intended targets.

130. The Regional Forensic Network should liaise with the Learning Disability Implementation Team and take the lead role in promoting the planning and development of community forensic learning disability services.

131. The proposed needs assessment and service mapping exercise (Chapter 8) should include the gathering of information to guide the further development of community forensic learning disability services, following the initial development of a regional service.

132. Immediate measures should be taken to create a regional community forensic learning disability service linked to an inpatient assessment and treatment service. This regional service should support the development of 5 locally based and regionally co-ordinated community forensic learning disability teams. These teams must have sufficient capacity to fulfill the same purposes as those identified for other community forensic services (Chapter 9).

133. Community Forensic Learning Disability Teams must be developed with the necessary staffing levels and range of skills to meet the needs of users and carers. The proposed regional team is likely to require similar staffing levels and resources to the Community Forensic Teams proposed at Chapter 9, with the addition of access to speech and language therapy services.

134. The Regional Forensic Network should ensure that community forensic learning disability services in Northern Ireland develop risk assessment and management policies, procedures and protocols that represent best practice and co-ordinate with the arrangements of interconnecting services.

135. The Regional Forensic Network should promote and co-ordinate the development of performance and quality standards for community forensic learning disability services and

ensure that there are robust quality assurance mechanisms including internal audit and independent external inspection and review.

136. The Regional Forensic Network should co-ordinate with the regional body with responsibility for mental health promotion to ensure that community forensic learning disability services contribute to mental health promotion and public education.

137. The Regional Forensic Network should co-ordinate the development of information and research strategies for community forensic learning disability services. It should promote the use of information technology to support and enhance multi-disciplinary and inter-agency communication and information-sharing, in accordance with agreed protocols.

138. The DHSSPS must ensure that development and maintenance of community forensic learning disability services is supported by robust workforce planning and provision of opportunities for staff to avail of learning, development and support.

139. The development of community forensic learning disability services requires additional sustainable funding from the relevant sources. Funding arrangements must support the joint co-ordinated planning and delivery of services. There should be mechanisms to demonstrate that monies made available to services have reached their intended targets.

140. The DHSSPS and the Northern Ireland Office and relevant Criminal Justice Agencies should produce a comprehensive interagency and community response to help offenders reduce their risks of offending and to provide protection to the public from high risk sexual and violent offenders, irrespective of whether or not they suffer from mental disorder. This Risk Assessment and Management Framework should include:

- the legislative framework, including options to provide courts with risk assessments such as a risk assessment order and sentencing options such as an order for lifelong restriction;
- processes, methods and standards of risk assessment, risk management and offender therapy programmes;
- interagency strategies and working arrangements, including information sharing and other joint protocols and procedures;
- development of best practice, guidance and quality assurance mechanisms;
- training in risk assessment, risk management and offender therapy methods;
- accreditation of practitioners;
- the services required for the assessment and management of risk and the provision of offender therapies, including specialist facilities in conditions of security and in the community;
- the development of research strategies and methods of research and evaluation; and
- assessment of the workforce requirements and the provision of appropriate workforce planning and funding to meet the identified needs.

141. The Regional Forensic Network should ensure that all inpatient and community forensic services in Northern Ireland develop risk assessment and management policies, procedures and protocols that represent best practice and co-ordinate with the Risk Assessment and Management Framework.

142. The Regional Forensic Network should promote and co-ordinate the development of performance and quality standards for risk assessment and management by forensic services and ensure that there are robust quality assurance mechanisms including internal audit and independent external review.

143. The DHSSPS should revise current Discharge Guidance to ensure that it is compatible with the principles recommended by this Review and is supported by training and other appropriate resources.

144. The DHSSPS and NIPS must ensure that services are developed for people with personality disorder, including offenders. The services require co-ordinated joint approaches by both the Criminal Justice System and the Health and Social Services. Service users, carers and their advocates must be involved in service planning and delivery

145. The DHSSPS should ensure that assessment and treatment services are made available to offenders suffering from personality disorder along with support for their carers. Services should be provided in prisons and in the community. Services in the community should comprise outpatient, day patient and therapeutic community services. In the prisons outpatient and day patient services should be provided. A residential secure service should also be developed.

146. The DHSSPS should commission a detailed assessment of needs to inform the planning of services for offenders with personality disorder.

147. Service providers must ensure that services for the assessment and management of personality disorder are supported by the development of policies, procedures and protocols that recognise the respective responsibilities of all key stakeholders and that coordinate with the proposed Risk Assessment and Management Framework.

148. The commissioners and providers of services for offenders with personality disorder must ensure that services have strong quality assurance and governance arrangements including internal audit and independent external inspection and review.

149. The Regional Forensic Network should co-ordinate with the regional body with responsibility for mental health promotion to ensure that forensic services for people with personality disorder contribute to mental health promotion and public education, including contributing to understanding of the development of personality disorders and the most effective ways of preventing them.

150. The Regional Forensic Network should promote the development of information and research strategies for forensic services for people with personality disorder. Research should be conducted into the needs of offenders with personality disorder and into the efficacy of therapeutic interventions.

151. The Regional Forensic Network should promote the use of information technology to support and enhance multi-disciplinary and inter-agency communication and information-sharing, in accordance with agreed protocols.

152. The DHSSPS must ensure that robust workforce planning systems are developed to ensure the recruitment, training support and retention of suitable staff to support the development of services for offenders with personality disorder.

153. The development and maintenance of forensic services for the assessment and treatment of high risk offenders and individuals suffering from severe personality disorder requires appropriate funding from the relevant agencies. This should be delivered in accordance with a long term plan that ensures sustainable development of services. There must be mechanisms that demonstrate that monies made available to services have reached their intended targets.

154. The Regional Forensic Network should co-ordinate a programme of training for staff in the identification, assessment, treatment and care of people suffering from Asperger's Syndrome or High Functioning Autism (AS/HFA) in Forensic Mental Health and Learning Disability Services and the Criminal Justice System.

155. The DHSSPS in partnership with Criminal Justice Agencies should commission a regional needs assessment to ascertain the prevalence of AS/HFA within the Criminal Justice and Forensic Services in Northern Ireland and to assess the needs of users and carers.

156. The DHSSPS should promote research into AS/HFA, including its relationship with offending behaviour, the effectiveness of specific psychological and environmental interventions, the development of models of service models and the definition of acceptable outcomes.

157. Service commissioners and providers must ensure that services are gender sensitive. Planning and development of forensic services must take account of the needs and wishes of service users, their advocates and carers.

158. The Regional Forensic Network should co-ordinate the development of gender sensitive policies in all forensic services.

159. The proposed assessment of needs for secure provision (Chapter 8) should consider options to meet the needs of service users in a manner that is gender sensitive. This should include consideration of whether a separate low secure facility is more appropriate to the needs of women service users than the current provision in Shannon Clinic.

160. Community services should be provided individually to male and female users on the basis of individual needs and must be gender sensitive.

161. Service providers must ensure that staff in all Forensic Services receive training to ensure that services are gender sensitive.

162. The DHSSPS, the Regional Forensic Network, service commissioners and providers must ensure that planning and development of all inpatient and community mental health and learning disability forensic services incorporate and integrate a range of multi-disciplinary psychotherapeutic approaches.

163. All clinical staff working in forensic services must be provided with the appropriate opportunities and support to develop high levels of psychotherapeutic knowledge and skill.

164. The planning and delivery of forensic services must also include the provision of services by specialist Psychotherapists and Forensic Psychotherapists.

165. The DHSSPS must ensure that development and maintenance of forensic mental health and learning disability inpatient and community services is supported by robust workforce planning that takes account of the need to recruit and retain specialist Psychotherapists and Forensic Psychotherapists and to provide supervision, support and training to staff working in forensic services.

168. The Review recommends the establishment of a Regional Forensic Network to co-ordinate the planning and delivery of Forensic Services at regional and local levels.

169. Forensic Services should be commissioned on a regional basis.

APPENDIX

The Bamford Review of Mental Health and Learning Disability Services (Northern Ireland)

In October 2002, the Department of Health, Social Services and Public Safety (DHSSPS) commissioned an independent review with the following terms of reference:

(i) To carry out an independent review of the effectiveness of current policy and service provision relating to mental health and learning disability, and of the Mental Health (Northern Ireland) Order 1986.

(ii) To take into account:

- the need to recognise, preserve, promote and enhance the personal dignity of people with mental health needs or a learning disability and their carers;
- the need to promote positive mental health in society;
- relevant legislative and other requirements, particularly relating to human rights, discrimination and equality of opportunity;
- evidence-based best practice developments in assessment, treatment and care regionally, nationally and internationally;
- the need for collaborative working among all relevant stakeholders both within and outside the health and personal social services sector;
- the need for comprehensive assessment, treatment and care for people with a mental health need or a learning disability who have offended or are at high risk of offending; and
- issues relating to incapacity.

(iii) To make recommendations regarding future policy, strategy, service priorities and legislation to reflect the needs of users and carers.

The Review was structure into a Steering Committee and 10 Expert Working Committees:

- Social Justice and Citizenship;
- Legal Issues;
- Learning Disability;
- Adult Mental Health;
- Mental Health Promotion;
- Child and Adolescent Mental Health;
- Dementia and Mental Health Issues of Older People;
- Alcohol and Substance Misuse;
- Forensic Services; and
- Needs and Resources.

Remit of the Forensic Services Committee

The Forensic Services Committee adopted the following remit:

'To examine the needs and make recommendations for services for mentally disordered adult offenders and those with similar needs including mentally disordered people:

- *In police stations*
- *Attending court*
- *On bail*
- *In prisons and young offenders' centres*
- *In contact with probation services*
- *Requiring specialised forensic services:*
  - *high, medium & low security inpatient settings*
  - *community forensic services, including both statutory and independent services'*

The Methods Adopted by the Forensic Services Committee

The membership of the Forensic Services Committee (the Committee) includes broad representation from service users and carers, the wider community, Criminal Justice Agencies and health and social services in both the statutory and independent sectors.

The members of the Committee met regularly and also consulted with other key stakeholders. The Committee arranged a series of one – day meetings to which there was an open invitation. These meetings examined key issues with the assistance of presentations and discussion from national and international experts. In addition it commissioned a review of the published scientific literature to ensure that its recommendations were evidence-based and it commissioned a survey of stakeholder views. That review of the scientific literature and of stakeholder views has been published separately[1] and its key findings have been incorporated within this report.

The Committee considered and made recommendations on the values and principles that should guide the development and delivery of forensic services. From these it developed standards which it then applied to the current components of forensic services in Northern Ireland. This process helped highlight service needs. The Committee then collated the identified needs and formulated recommendations to remedy them, considering the components of forensic services individually and collectively, as an interconnecting system. The Committee prioritised its recommendations, identifying the key elements for change and the sequences in which such changes should be made. This draft report has been compiled and submitted for public consultation before the Committee report was finalised.

FORENSIC SERVICES WORKING COMMITTEE

Membership:

Convenor: Dr Fred Browne - Consultant Forensic Psychiatrist

- Prof David Bamford - Chair of MH & LD Review & UU
- DS Andrew Bailey - PSNI
- Dr John Farnan - Forensic Medical Officer
- Dr Bill Lockhart – Youth Justice Service
- Dr Colin Milliken - Consultant Psychiatrist
- Brendan Fulton - Probation Board NI
- Cathy McPhillips - SHSSB
- Raymond Kitson – Public Prosecution Service
- Dr Jackie McCall – EHSSB
- George Keatley - Court Service
- Dr Philip McClements – NI Prison Service
- Anne Rafferty - Criminal Justice Policy Division, NIO
- Winston McCartney - Advocate
- Deborah Devaney - Carer
- Dr Ian Bownes - Consultant Forensic Psychiatrist
- Dr Harry Kennedy - Consultant Forensic Psychiatrist
- Dr Geraldine Henry - Consultant Psychiatrist
- Geraldine O'Hare - Probation Board NI
- Rev Trevor Williams
- Maureen Warner - Occupational Therapist
- Emmet Murray – Forensic Psychologist
- Brian Simpson - WHSSB
- DS Andrew Thompson - PSNI
- Dr Ian McMaster - DHSSPS
- David McCrum – Service User
- DI Gary Mullan – PSNI
- Sally Newton – NI Prison Service
- Prof Jackie Bates-Gaston – NI Prison Service
- Noel McKenna – Independent Monitoring Board

GLOSSARY

‘Forensic’, ‘Services’ and ‘Forensic Service Users’

The word ‘*forensic*’ is derived from the Latin word ‘*forum*’, meaning ‘the court’ and thus the word ‘*forensic*’ means ‘relating to the courts’ or, more widely, ‘relating to the Criminal Justice System’. This report examines the needs of mentally disordered offenders and those with similar needs, such as those who suffer from mental illness or personality disorder and who engage in dangerous, persistently challenging or aggressive behaviour. Forensic Services comprise a range of components, such as services to people in prison, community forensic services and secure inpatient services. In keeping with the other reports from this Review the term ‘service user’ is used in preference to other terms such as ‘patient’ or ‘client’. Within the context of this report ‘service user’ has been used to refer to certain individuals who suffer from mental disorder and who require forensic services to meet their needs. It should be noted that forensic health and social services are not yet well developed in Northern Ireland and that the use of the term ‘service user’ does not necessarily indicate that a forensic service currently exists to adequately meet their needs.

Psychiatric Hospital

The term ‘Psychiatric Hospital’ is used to include hospitals that provide inpatient treatment and care for those suffering from mental illness and from learning disability.

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THE BAMFORD REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY
(NORTHERN IRELAND)

HUMAN RIGHTS
AND
EQUALITY OF OPPORTUNITY

October 2006

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HUMAN RIGHTS
AND
EQUALITY OF OPPORTUNITY

CONTENTS

FOREWORD

Respect for human rights and promotion of equality of opportunity: these values underpin the Bamford Review of Mental Health and Learning Disability (Northern Ireland) – not only in the way in which we have conducted our work, but also in the overarching vision we have for the future strategic development of services in Northern Ireland for people with a mental health problem or learning disability.

This report is, therefore, a key product of the Review and provides the ethical foundation on which our proposals for service reform and modernisation, including legislative reform, have been based. Much of the detail of how this rights-based vision can be achieved in practical terms is given in the other reports from the Review and, in particular , the forthcoming report on Promoting Social Inclusion.

To make a reality of this vision of full citizenship for people with a mental health difficulty or a learning disability will require commitment by Government and co-ordinated action across several Northern Ireland Departments and public bodies. We look to the Department of Health, Social Services and Public Safety (DHSSPS) to give the lead in this and in ensuring that the recommendations outlined in this report are taken forward.

I thank Christine Eames and her Group for their commitment to producing this report, which I commend to you.

Roy J McClelland (Professor)
Chairman

October 2006

OVERVIEW

This report is the result of intensive work over a prolonged period of time. Its recommendations are the outcome of much deliberation, consultation and shared experience. Our work benefited greatly from the knowledge of others who assisted us and also from meetings with experts and stakeholders. The recommendations it presents are broad, they challenge assumptions and will require both financial and human resources to ensure proper implementation by the number of departments and agencies involved.

The report identifies and discusses issues against domestic and international standards of Human Rights and Equality, and in so doing seeks to remove barriers to the exercise of these rights: to help remove stigma and prejudice; to ensure that accessible information is provided, and shared, enabling access to services; to acknowledge the importance of the recommendations for carers and users of services, and to give protections where necessary.

The working group established to examine these issues was comprised of people from a wide range of disciplines and with a wide range of experience united in a commitment to the aims and principles of the Bamford Review. Clinicians, lawyers, practitioners, users and carers all brought their understanding of the needs under discussion to the table. It was for all of us, not just a case of making a contribution, but a learning experience.

Such a report as ours may well have been completed in other ways, especially if it were restricted to a single discipline or focus. However it was the opinion of the group that the method adopted best reflected and gave expression to the depth of experience and the diverse representation amongst us. The group was also conscious of the remit given to it by the Steering Committee of the Review, which was of fundamental importance and guided all of our work.

I would like to thank all those who responded to the consultation process in the summer of this year. This report has been improved and its recommendations strengthened as a result this and we are grateful to all those who gave such careful consideration during this important stage. I would wish to assure all those who responded that each reply received the utmost consideration against our remit.

Finally, I would like to thank all those who gave so generously of their time and their experience, and showed such immense commitment to the spirit of the Review and to our particular task within it. On behalf of all the members of the group, I want to thank Roy Keenan and Sean Ferrin of the Support Team for their unfailing help and work in making this report a reality.

Christine Eames
October 2006

ABBREVIATIONS

Throughout the report a number of abbreviations are used. These are:

ASW	- Approved Social Worker
CAMHS	- Child and Adolescent Mental Health Service
Children Order	- The Children (Northern Ireland) Order 1995
DDA	- The Disability Discrimination Act 1995
DHSSPS	- The Department of Health, Social Services and Public Safety
ECHR or the Convention	- The European Convention on Human Rights
Equality Commission	- The Equality Commission for Northern Ireland
European Court	- The European Court of Human Rights
EU	- The European Union
MHO or the Mental Health Order	- The Mental Health (Northern Ireland) Order 1986
NI	- Northern Ireland
NICCY	- Northern Ireland Commissioner for Children and Young People
Section 75	- Section 75 of the Northern Ireland Act 1998
The Review	- The Bamford Review of Mental Health and Learning Disability (Northern Ireland)
UK	- The United Kingdom
UN	- The United Nations
UNCRC	- The United Nations Convention on the Rights of the Child 1989
USA	- The United States of America

CHAPTER 1

INTRODUCTION

THE REVIEW

1.1 In October 2002, the Department of Health, Social Services and Public Safety (DHSSPS) commissioned an independent Review of law, policy and practice relating to mental health and learning disability. One of the main factors influencing this decision was to ensure that this law, policy and practice was in accordance with human rights and equality law.

HUMAN RIGHTS AND EQUALITY SUB GROUP

1.2 The Human Rights and Equality Sub Group, whose membership is at Annex 1, is one of two Groups within the Review's Social Justice and Citizenship Expert Working Committee. The other Sub Group has been preparing a separate report on Promoting Social Inclusion, which will be published in the near future.

1.3 The Human Rights and Equality Group's remit was to:

- consider relevant legislative and other requirements, particularly relating to human rights, discrimination and equality, in relation to people with a mental health need and/or a learning disability; and

- bring forward a set of principles, proposals and recommendations.

1.4 In addition, the Group played a key role within the wider Review, by formulating a set of overarching human rights and equality guidelines against which each Working Committee could test their discussions and recommendations.

1.5 In discharging its remit, the Group recognised that there are people with special needs - for example, those with eating disorder, brain injury, Autistic Spectrum Disorder, or people with a learning disability who have complex needs - who are especially vulnerable to breaches of their human rights and to discrimination. These and other groups requiring special attention and priority have been identified in the separate reports produced by the Review.

1.6 There are also specific human rights and equality issues faced by vulnerable, marginalised and minority groups within Northern Ireland, who may also have a mental health difficulty or a learning disability, such as the gay/lesbian community, homeless people, asylum seekers, members of ethnic minorities, or those in contact with the criminal justice system. It was never the Sub Group's brief to consider in detail all of the issues affecting such groups, but it is important to stress at the outset that the principles outlined in Chapter 2 and many of the recommendations throughout the report apply equally to all these groups.

1.7 The Group initially agreed a work plan comprising a number of topics raising potential human rights and equality of opportunity questions in relation to the assessment, care and treatment of people with a mental health problem or a learning disability. The plan took account of the comments made by a wide range of statutory, voluntary, community and other stakeholders, who responded in the autumn of 2002 to Professor Bamford's request for initial submissions to the Review on the strengths and weaknesses of current legislation, policy and service delivery for people with a mental health problem or a learning disability.

1.8 Papers on most of these work plan topics were provided by members for discussion and agreement. The Group also organised a consultation seminar on Advocacy for the entire Review, as part of its consideration of this subject. On the other issues identified, the Group contributed through the reports being prepared by relevant Working Committees.

1.9 Members of the Group also attended a Mental Health Tribunal hearing and have liaised with the Experts by Experience, Equal Lives and Carers' Reference Groups within the Review, whose contributions through their own experience of services have been invaluable.

STRUCTURE OF REPORT

1.10 The Group considered it was essential that the papers which informed its discussions were made available and these have been placed on the Review's website, at www.rmhldni.gov.uk. Members were also conscious that some of the issues are complex and their essence needed to be distilled into short, concise papers. These papers comprise this report and cover, for example, the key human rights and equality issues and any recommendations on the subjects considered.

CONTEXT OF REPORT

1.11 It is important also to point out that the Group's work was essentially to examine the human rights and equality issues which may arise (or could potentially arise) from the operation of current legislation, mainly the Mental Health (Northern Ireland) Order 1986. Many of the report's recommendations reflect this, but they also signify how a future legislative framework could address these issues. In this way, therefore, this report foreshadows a substantial revision of legislation which the Review will be proposing in a separate report.

1.12 Similarly, many of the issues discussed overlap with and are expanded upon in the Promoting Social Inclusion report, currently subject to separate consultation. Examples of such issues are equality of access to education and employment opportunities.

ACCESSIBLE FORMATS

1.13 Accessible versions of this report, including a young person's accessible version, have also been produced. These can be obtained from the Review's Support Team, Annexe 6, Castle Buildings, BT4 3PP (Tel No 9052 3470) and are posted on the Review's website at www.rmhldni.gov.uk. Requests for copies in braille, audio cassette, Irish and Chinese (Mandarin) should also be sent to the Support Team at this address.

TERMINOLOGY

1.14 The report's remit concerns people with a mental health problem or a learning disability , or both; and for convenience we use the phrases:

- "mental health difficulties or a learning disability";
- "a mental health problem or a learning disability"; or
- "mental ill-health or a learning disability"

as broad, generic terms, interchangeably throughout the document, unless the issue under consideration relates specifically to people with a mental health problem or to people with a learning disability.

CHAPTER 2

LAW, STANDARDS, POLICY AND PRACTICE

LAW AND STANDARDS

2.1 The main sources of human rights and equality law and standards relating to Northern Ireland are:

- the Human Rights Act 1998 (which made the European Convention on Human Rights (ECHR) enforceable in Northern Ireland courts);
- Section 75 of the Northern Ireland Act 1998;
- anti-discrimination legislation in place in Northern Ireland, including the Disability Discrimination Act 1995 and the Disability Discrimination (Northern Ireland) Order 2006;
- the Race Relations (Northern Ireland) Order 1997;
- the United Nations Declaration on the Rights of Disabled Persons;
- the United Nations Declaration on the Rights of Mentally Retarded Persons 1971;
- the United Nations Convention on the Rights of the Child (UNCRC) 1989;
- the United Nations Convention against Torture;
- the European Social Charter;
- the International Covenant on Civil and Political Rights;
- the International Covenant on Social, Economic and Cultural Rights;
- the Convention on the Elimination of Discrimination against Women;
- the Convention on the Elimination of Racial Discrimination;
- the Mental Health Care Principles;
- The Criminal Justice (No. 2) (Northern Ireland) Order 2004.(The “Hate Crimes” legislation); and
- legislation relevant to the care, welfare and support of children and adults with a mental health problem or a learning disability, such as the Children (Northern Ireland) Order 1995, the Chronically Sick and Disabled Persons Act 1978 and the Disabled Persons (Northern Ireland) Act 1989.

GUIDELINES

2.2 At the outset, informed by the Review's overall Strategic Vision, which emphasises, for example, non-discrimination, equality, justice and fairness, partnership with service users and carers, reciprocity and respect for autonomy, the Group drafted a set of overarching and more specific human rights and equality guidelines. These aimed to inform the conduct of **all** the Review's Expert Working Committees and their Sub Groups, and set the context for their work.

2.3 These guidelines, which apply to everyone with mental health difficulties or a learning disability, regardless of age, and their circumstances (eg those in community or hospital settings, or in contact with the criminal justice system) are:

- The Review recognises that everyone has human rights and must be valued for his or her self-worth. States and international organisations have a duty to uphold and protect these rights.

- Putting human rights and equality principles at the centre of law, policy and delivery of services for people with a mental health problem or a learning disability is a legislative imperative because of international and domestic law.

- These principles also need to be taken into account in professional codes of conduct and practice.

- Given that people live in social settings, the human rights of any individual have to be considered in the context of relevant and often competing rights.

- Human rights, including the rights of people with a mental health problem or a learning disability, should not be arbitrarily diminished.

- There are circumstances, however, when it may be appropriate to curtail a person's human rights, but this should be limited to the minimum extent necessary, and a person whose rights have been curtailed should be entitled to appropriate services, including care, treatment and support (reciprocity of rights).

- Adequate resources must be put in place to assist recovery and to provide support for people with mental health difficulties or a learning disability.

- All public bodies must uphold these human rights and equality duties in performing their functions. Ultimately, law and decision-makers, including members of this Review, have to strike the appropriate balance in relation to the relevant rights and interests.

- However, rights of themselves are of little use unless people enjoy the protection offered by human rights in their daily lives. It is important that people know about their rights and, where these appear to have been breached, are able to enforce them.

- To enable people with a mental health problem or a learning disability to exercise the same rights as others, additional support, information and training may be required to maximise understanding and participation.

- Ensuring equality of opportunity can also mean making structural changes, tackling discrimination and addressing the assumptions and attitudes of others about mental health or learning disability.

- People with a mental health problem or a learning disability should also enjoy the implementation of their right to education, as appropriate.

CHILDREN AND YOUNG PEOPLE

2.4 Children are a particularly important and vulnerable group. All legislation, policy, services and treatment to children and young people in both mental health and learning disability settings should be compliant with international standards (in particular , the detailed provisions of the UNCRC) and ensure that they enjoy the same rights and opportunities as other children. This will mean the provision of age-appropriate facilities.

2.5 The principles and provisions of the UNCRC must inform the Review’s recommendations on children and young people, and the implementation of those recommendations. These principles must be read in conjunction with the Guidelines outlined at paragraph 2.3.

2.6 It is also important to stress that the onset of severe mental illness often occurs in early adolescence, often transforming the lives of young people previously fully engaged in education, leisure and other social and cultural activities.

RESOURCES

2.7 Putting these principles into practice in the day-to-day delivery of services is not, therefore, an optional extra: and to do so will require additional resources.

2.8 The Review recognises that expenditure on mental health and learning disability services in Northern Ireland compares poorly with some other parts of the United Kingdom. Too often, these services are the "poor relations" in comparison with other programmes of care.

2.9 It is essential that people with mental health difficulties or a learning disability have equal access to and benefit from resources allocated by Government. Boards and Trusts must ensure that adequate resources are allocated to meet the needs of people with mental health difficulties or a learning disability in their areas. The Review acknowledges the continuing work of the Department of Health, Social Services and Public Safety on its Capitation Formula, by which the available resources are allocated among the four Boards. The Formula is also used by the Boards to inform the subsequent deployment of their resources to local areas.

2.10 The Review also acknowledges this Department's more recent introduction of a Strategic Resource Framework. This provides an analysis of the way in which the Boards plan to spend the resources available to them at the start of each year . It also enables the Department and the Boards to track resource deployment by locality . In this way it can influence the funding available to local areas and ensure that they are receiving (or will receive) a fair share. However , such locality-based funding can disadvantage small, complex, geographically dispersed populations, such as those with mental health problems or a learning disability, where services are outside the areas in which they live.

2.11 Compliance with human rights and equality obligations is an integral part of the reform and modernisation of services for people with a mental health problem or a learning disability. To achieve this, additional resources must be made available, and must be distributed and spent in an equitable way.

CHAPTER 3

ACCESS TO RIGHTS

BARRIERS TO EXERCISING RIGHTS

3.1 People with mental health difficulties or a learning disability experience a range of barriers which prevent them from exercising their rights, including:

- assumptions made about their capacity;
- lack of knowledge and/or support to exercise rights;
- unequal access to services and opportunities in employment, education, transport, and access to and participation in the justice system;
- stigma and prejudice; and
- staff attitudes.

Assumptions about Capacity

3.2 Assumptions are often made by others about the capacity of people with mental health difficulties or a learning disability to participate in or contribute to the life of their community, or to make decisions. These assumptions are often due to ignorance and prejudice, arising from a lack of information and understanding about mental health or learning disability.

Lack of Knowledge about Rights and Support to Exercise Rights

3.3 Historically, people with mental health difficulties or a learning disability have been viewed as individuals in need of care and protection rather than individuals with rights. Traditionally, this care has been provided in institutions which isolated and separated those involved from the life of their local community. More recently, there has been a shift towards recognising that many of the difficulties experienced by people with disabilities arise from the structures and systems of society rather than in the person.

3.4 Most people with a learning disability need extra support to understand and to exercise their rights. The fact that information about rights is not produced in a range of formats that are accessible causes particular difficulties for them. The Review, therefore, welcomes DHSSPS' intention to address this in the next phase of its accessible formats project, as part of its work to promote equality and human rights.

Unequal Access to Services and Opportunities

3.5 Evidence shows that people with mental health difficulties or a learning disability do not have access to the same range of education, healthcare, leisure, housing or employment services and opportunities as other people in Northern Ireland. This is due, largely, to the failure of mainstream services to take into account their specific and distinctive needs when planning or delivering services. These issues are identified in the Review's other reports, particularly that on Promoting Social Inclusion.

3.6 The introduction of anti-discrimination legislation, including the Disability Discrimination Act 1995 and the obligation placed on public authorities to promote equality of opportunity through Section 75 of the Northern Ireland Act 1998, has gone some way to address the exclusion and disadvantage that people with mental health difficulties or learning disability experience. Section 75 is, in fact, a positive and proactive requirement, which requires public authorities to address any identified adverse impact by considering any mitigating measures, or alternative policies which might better achieve equality of opportunity .

Stigma and Prejudice

3.7 Ignorance, stigma and fear around mental health and learning disability can result in discrimination and lead some to erroneously believe that people with a mental health difficulty or a learning disability do not have the same rights as others in society Prejudice and ignorance can also mean that the participation of people with a mental health difficulty or a learning disability is not sought or welcomed, and their contributions not adequately recognised or valued. Stigma may also inhibit people with mental health difficulties and a learning disability from becoming included, and add to their isolation and exclusion.

Staff Attitudes

3.8 Staff in all public services have a key role to play in removing the barriers faced by people with mental health difficulties or a learning disability in exercising their rights. Staff working in health and social care have a particular responsibility to ensure that the way they plan, design and deliver services empower and respect the rights of people with mental health difficulties or a learning disability.

CARERS

3.9 The absence of services to support people with mental health difficulties or a learning disability can add to the stress and anxiety experienced by carers. It can also result in carers not having the same opportunities as others in their community to work, to rest and to access services in their own right.

3.10 Carers should not, as a consequence of their caring role, be discriminated against in areas such as education and employment. Carers fall under the Section 75 category of "people with dependents", whereby current and potential adverse policy impacts need to be acknowledged, and either addressed, or reason given as to why they cannot be addressed. Recognition, acknowledgement, support, information, respite, flexibility and choice are core requisites in promoting carers' rights to equality of opportunity. Carers also have their own specific personal needs which must be fully assessed and, where appropriate, met.

3.11 Carers are equal partners in the provision of care and should be provided with appropriate information and training for their caring role. They have the right to be involved in decisions, not only about their own situation, but also where services are being designed to support them, such as in Boards, Trusts, and other agencies involved in planning, monitoring and evaluation. These organisations should actively involve carers as well as representatives of carers' groups. Capacity should be built among carers, including providing information and training to enable them to fulfil their caring and representative roles.

3.12 In most situations the carer or family is the key source of information on the person needing support. Yet carers often feel that their knowledge of the person and their caring expertise are neither recognised nor valued. Care planning for the service user should be explicit about all who contribute to care, and the nature of their contribution. Creating partnerships – between carers and those professionals who provide services, both to the carers and to the person for whom they are caring - are essential to providing effective support. These partnerships must recognise the expertise of carers, ensuring that they are meaningfully involved in the planning and delivery of services.

Recommendations

1. **The Government and the Commissioners for Human Rights, Children and Equality must actively promote the rights of people with mental health difficulties and people with a learning disability, and provide accessible information about these rights to them.**

2. **Public, voluntary and independent sector staff, including front line staff and policy makers, must receive training on human rights and equality issues in relation to people with a mental health problem or a learning disability. This requirement must be reflected in contractual arrangements.**

3. **Mental health and learning disability services must reflect and be sensitive to the different religious, ethnic, racial and cultural backgrounds of people and groups in Northern Ireland. Services must comply with the equality obligations of Section 75 of the Northern Ireland Act 1998 and take account of those who experience multiple disadvantage.**

4. **Government and public bodies must ensure that people with mental health difficulties or learning disability have equal access to the same range of services and opportunities as other people in Northern Ireland.**

5. **Government and public bodies must actively address issues of stigma and prejudice and implement action plans for this purpose.**

6. **Government and public bodies must address the inequalities experienced by carers and uphold their right to have their needs recognised and met. Carers must have their expertise recognised and respected and be fully involved as equal partners in the planning and delivery of services.**

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CHAPTER 4

THE RIGHT TO VOTE, TO FOUND A FAMILY AND TO LIFE

CHANGING PERCEPTIONS AND NEEDS

4.1 Over the last 20 years or so, there has been a shift away from perceiving people with disabilities as the recipients of care, protection and treatment, towards recognising them as individuals who have rights, but who may not fully enjoy these rights.

4.2 Linked to this has been an increasing emphasis on acknowledging the inherent value of disabled people, of empowering them, maximising their autonomy and self-determination and tackling the barriers that stop them enjoying the same rights as others.

4.3 There has also been a growing recognition that some groups of disabled people - such as children, women, older people and people from different ethnic backgrounds - experience particular difficulties.

4.4 The interdependence of civil, political, economic, social and cultural rights is particularly relevant for disabled people, since many will rely on additional supports to exercise their rights.

EXERCISING RIGHTS

4.5 Because a person has a mental health difficulty or a learning disability does not of itself mean that he or she is not capable of exercising his or her rights. Assumptions about capacity can, of course, interfere with a person's right to make decisions about all aspects of his or her life. The issues in each instance are whether:

- the individual has the competence to understand the nature and purpose of the activity or decision in question; and
- systemic barriers exist which prevent the individual from taking advantage of the rights they are afforded.

4.6 The Sub Group concentrated on these issues in relation to three particular rights:

- entitlement to vote;
- marriage, sexual relations and the right to found a family; and
- the right to life.

ENTITLEMENT TO VOTE

Eligibility to Vote

4.7 Eligibility to vote in elections in Northern Ireland is restricted by criteria relating to age, citizenship and residency. To vote, a person must also be listed on the relevant Northern Ireland register of electors for a particular election.

Common Law

4.8 There are no references to people with mental health difficulties or a learning disability in current electoral law . The only reference is in common law , which uses outdated terminology and states that "idiots" cannot vote and that "lunatics" can only vote in lucid intervals.

4.9 The Electoral Commission, which is responsible for encouraging public confidence and participation in the electoral process, recognises that the terms "idiots" and "lunatics" are "anachronistic" and "give no guidance to the Electoral Registration Officer".

4.10 The Commission adds, however, that common law incapacity cannot be disregarded and that it would be wrong to register a person if there were grounds to believe that he or she lacked the capacity to vote because of mental incapacity.

4.11 The guidance produced by the Commission states that the general assumption should be to register people with mental health difficulties or a learning disability.

4.12 The Commission goes on to suggest that a person who is registered as an elector or entered in the list of proxies, cannot be refused a ballot paper or be excluded from voting on the grounds of mental incapacity.

Legal Incapacity to Vote

4.13 There are two factors which determine whether a person with a mental health difficulty or a learning disability can vote:

- whether he or she has a legal capacity to vote; and
- whether he or she has a place of residence for voting purposes.

4.14 Legal incapacity to vote has been defined as “some quality inherent in a person which…either at common law or by statute deprives him of the status of a Parliamentary elector”.

4.15 If a person with a mental health difficulty is in hospital on an informal basis or is subject to guardianship, that fact in itself does not place him or her under a legal incapacity to vote. His or her competency is still a question of fact.

Place of Residence

4.16 Previously the legislation distinguished between detained and voluntary patients in hospital. In addition, detained patients were not able to treat the hospital where they were detained as their place of residence for the purposes of electoral registration, and whether they could register as resident at a place outside the hospital was a question of fact to be determined by the Electoral Officer.

4.17 A person who had been detained, therefore, for more than six months was likely to experience difficulties in registering as resident at their former address.

4.18 The Representation of the People Act 2000 enacted provisions which are designed to enable persons in psychiatric hospitals to register to vote whether they are detained or voluntary patients (unless they are detained as a result of criminal activity in which case they are disfranchised).

4.19 Under the Act, a mental hospital is defined as meaning any establishment maintained wholly or partly for the reception or treatment of persons suffering from any form of mental disorder as defined by the Mental Health (Northern Ireland) Order 1986.

4.20 A new concept introduced by the 2000 Act is the “declaration of local connection”. This enables patients in a hospital to register by treating them as resident at the address which they have declared, which may be an address where they would be living if they were not a patient, or an address in the UK where they have lived at any time.

The Electoral Fraud Act (NI) 2002

4.21 Research carried out by the Electoral Commission into the first year of operation of the Electoral Fraud (Northern Ireland) Act 2002, highlighted concerns about the impact of the new registration process on people with a learning disability.

4.22 Provision had been made in the legislation for the registration form to be completed and signed by another person on behalf of the individual wishing to register. The person completing the form was asked to state the reason why the person wishing to register had not signed it. Where learning disability or mental health was given as the reason, a letter was sent from the Electoral Office, which is responsible for the management of elections in Northern Ireland, asking the person to confirm that the individual wishing to register had the mental capacity to vote.

4.23 The Electoral Commission concluded that "the individual registration process may have inadvertently impacted on people with learning disabilities, thus effectively disenfranchising hundreds of people who in the past may have voted".

Accessibility of Electoral Process

4.24 For many people with a learning disability the electoral rules and legislation are not the only barriers to taking part in the electoral process. Difficulties in getting to and gaining access to polling stations, the absence of information provided in a range of accessible formats, as well as the assumptions made by others about their capacity or interest in voting has militated against people with a learning disability exercising their right to vote.

4.25 The Review, therefore, welcomes the Government's proposals to review the law in the Electoral Administration Act 2006.

MARRIAGE

Capacity to Enter into a Marriage

4.26 In considering whether a marriage is invalid on the ground that one of the parties was suffering from a mental disorder at the time it was entered into, the test to be applied is whether he or she is capable of understanding the nature of the contract of marriage.

4.27 To understand the contract of marriage, a person must be capable of appreciating that it involves the duties and responsibilities normally attaching to marriage. Only a broad understanding of the nature of marriage is necessary. A mere understanding of the promise exchanged is not sufficient if the nature of the contract is not understood. The presumption is in favour of marriage and the burden of proof is on the party attempting to show lack of consent.

4.28 The right of a person with a mental disorder to marry - even if detained under the mental health legislation - is the same as that of any other person. The person must understand the nature and purpose of the marriage contract, must be capable of giving consent and must not be under duress.

Voidance of a Marriage by Reason of Mental Disorder

4.29 Under the Matrimonial Causes (Northern Ireland) Order 1978, a marriage is voidable if at the time of marriage either party, although capable of giving valid consent, was suffering (whether continuously or intermittently) from mental disorder within the meaning of the Mental Health (Northern Ireland) Order 1986, of such a kind or an extent as to be unfitted for marriage. In order to succeed, a petitioner must establish mental disorder which rendered the person incapable of living in a married state and of carrying out the duties and obligations of marriage.

Civil Partnerships

4.30 Individuals with mental health difficulties or a learning disability have the same rights as others in relation to civil partnerships.

The Right to Found a Family

4.31 Article 12 of the ECHR guarantees to men and women of marriageable age the right to marry and to found a family. The European Commission on Human Rights has considered two cases which raise the question of how far the rights guaranteed by Article 12 can apply to prisoners. The Commission's opinion was that the right to marry was in essence a right to form a legally binding association between a man and a woman and that this right could not be denied on the grounds that, as one of the partners was detained, the couple would not be able to live together.

4.32 The Government, in enacting the Marriage Act 1983, considered that these principles applied also to persons with a mental illness detained for substantial periods. Prior to the 1983 Act, detained persons did not have ready access to authorised places of marriage.The marriage of a detained person can be solemnised at the place where that person usually resides. A further liberalisation has been effected by the Marriage Act 1994.

4.33 Recent research studies, as well as the Review's Equal Lives report, have drawn attention to the growing numbers of parents with a learning disability. Traditionally, these parents were more likely than other parents to have had their children removed from them because of assumptions made about their ability to care, the lack of support available, as well as concerns about the welfare and protection of the children. The competing rights of parents and children to enjoy family life together, and the rights of children to be protected, present real and profound challenges to services (to ensure the welfare of children and to support adults with a learning disability) as well as the legal profession involved in family court proceedings. While the welfare of the child must be paramount, every effort must be made to provide adequate resources to support parents with a mental health difficulty or a learning disability.

Sexual Relations

4.34 While the law enables persons with a mental illness to be married provided they understand the marriage contract, it is silent as to whether married couples have a right to have a private place for sexual intercourse while detained in hospital, although such a right may be claimed under Articles 12 or 8 of the ECHR. The term "founding a family" in Article 12 has not been interpreted as referring to the consummation of marriage or having children.

4.35 Article 8 provides persons with the right to respect for their private and family life. This also applies to sexual life. The Department of Health advises that "given there is probably nothing in law to prevent a marriage from taking place, the hospital then has to consider whether facilities should be made available for consummation of the marriage, a matter raising questions about human rights. The decision whether to allow unsupervised visits should be based upon the following criteria:

- any risk one spouse may present to the other;
- overall security within the hospital;
- the social consequences of making available to certain patients privileges not available to others; and
- the availability of suitable facilities."

4.36 Current mental health legislation does place limits on the capacity of certain groups to engage in sexual activity. Whilst the aim of the legislation is to protect people with mental disorder from exploitation and abuse, it can also interfere with the freedom of some people with a mental disorder from developing relationships, engaging in sexual activity and marrying.

RIGHT TO LIFE

4.37 The Review's report on learning disability, Equal Lives, drew attention to research which indicates that people with a learning disability have higher mortality rates than people in the general population. The Disability Rights Commission, which operates in Great Britain, highlighted, too, in an evidence paper produced as part of its health inequalities investigation, the increased risk of early death for people with a learning disability and the higher levels of mortality rates for people with schizophrenia or manic depression.

4.38 The fundamental human right to life imposes on the Government an obligation to protect every person's right to life. This is linked to the provision of appropriate services, for example, the prevention of suicide and self-harm, as well as raising issues such as the provision of help and support after release from institutional care. The Review's report "Mental Health Improvement and Well-Being - A Personal, Public and Political Issue" deals with issues around suicide prevention.

4.39 The decision to impose or withdraw medical care or treatment raises complex ethical, legal and moral issues. Recent medical advances mean that many people of all ages are able to survive because of medical intervention and treatment. Doctors and other health care professionals are required to take into account the effects that a treatment might have on a person's "quality of life", even though the treatment itself might prolong an individual's life.

4.40 This already difficult decision is made more complicated in cases where a person has a severe or profound learning disability and where a person may be unable to express an opinion or make a decision.

4.41 The Review acknowledges the Department of Health, Social Services and Public Safety's "Good Practice in Consent" Guidelines, which it issued in 2003, and its objective that the process of consent is properly focused on the rights of the individuals concerned and their relatives.

Recommendations

7. Legislation dealing with capacity should be based on the presumption of an individual's ability to make a decision. Responsibility should be placed on those challenging or questioning a person's decision-making capacity to provide evidence of incapacity.

8. The continued use of common law in current electoral practice should be reviewed as a matter of urgency.

9. Government and public bodies should provide training and information to their staff to enable them to comply with the positive duty to protect everyone's right to life.

CHAPTER 5

EDUCATION RIGHTS

5.1 The right to education is a fundamental right under the UNCRC and ECHR, as incorporated by the Human Rights Act 1998.

5.2 The Review emphasises the importance of recognising the right of every child and young person to have access to a practical and efective education. It is of fundamental importance to any analysis of human rights and equality issues and should be explicitly reflected and recognised in any new legislative framework.

5.3 A practical and effective education includes the need for a fully accessible curriculum and examinations or qualifications process.

5.4 Government policy or funding priorities should not disadvantage people with a mental health problem or a learning disability by, for example, prioritising academic or vocational courses for funding student support, or by setting timescales for completion of certain qualifications. Particular attention needs to be paid to ensuring that children and young people with mental health difficulties or a learning disability, who present challenges to educational services because of the severity or complexity of their disability, enjoy equal access to education. Young people with mental health difficulties or a learning disability preparing to leave school should have access to continuing and stimulating opportunities to learn and develop their potential.

5.5 There should also be some redress to recognise the fact that children and young people with severe learning difficulties only received the right to education in 1986, which means that most adults with a learning disability did not enjoy the same rights as others in the community.

5.6 Similarly, people who have missed out on educational chances because of previous mental ill-health should be able to avail of "catch-up" programmes. (These social inclusion issues will be picked up in the Review's separate report on Promoting Social Inclusion.)

5.7 Careful attention must be paid to the educational provision for any child or young person who is deprived of liberty, as this engages the child's rights under Article 5 of the ECHR. The right to education in this context extends beyond school leaving age and applies to all children and young people. Moreover, the European Court's definition of education is broader than simply classroom teaching. All provision should be detailed carefully in individualised education/treatment plans and reviews.

5.8 Children and young people with a mental health difficulty or a learning disability have the right to an effective and practical education without discrimination under Protocol 1, Article 2 and Article 14 of the ECHR, as incorporated by the Human Rights Act 1998. These rights should be read in conjunction with those provided specifically for children and young people by Articles 2, 3, 12, 23, 28, 29 and 42 of the UNCRC.

5.9 The inappropriate placing of children and young people in adult hospital wards is a serious human rights and equality issue. In relation to the education rights of such inappropriately placed children and young people, the Review believes that these have been particularly adversely affected.

5.10 Article 14 of the ECHR, in conjunction with Protocol 1, Article 2 ECHR and Article 2 of the UNCRC require educational provision for children with a mental health problem or a learning disability to be provided on a non-discriminatory basis. It should promote equality. This is re-enforced by the new provisions introduced by the Special Educational Needs and Disability (Northern Ireland) Order 2005.

Recommendations

10. The right of every child and young person with a mental health problem or a learning disability to education should be explicitly recognised and reflected in any new legislative framework.

11. The Government must ensure that people with mental health difficulties or a learning disability have equal access to lifelong learning opportunities. This includes the funding and development of specific programmes and additional support, where needed.

CHAPTER 6

CAPACITY, INCAPACITY AND HUMAN RIGHTS

6.1 This chapter deals with the law in relation to capacity in Northern Ireland governing:

(a) the management of patients' property and affairs; and

(b) medical treatment and welfare provision.

LAW GOVERNING THE MANAGEMENT OF PATIENTS' PROPERTY AND AFFAIRS

6.2 While there is a legal presumption of capacity, two categories of persons are considered to lack capacity for legal purposes (and are regarded as persons under a disability):

- children; and

- adults without capacity e.g. "patients" i.e. persons, who by reason of mental disorder (as defined in Part VIII of the Mental Health Order) are incapable of managing or administering their property and affairs, which includes engaging in the legal process.

Persons Without Capacity and Representation in Court

6.3 The Official Solicitor to the Supreme Court of Northern Ireland looks after the interests of and represents certain "persons under a disability" as defined by the legislation. Generally speaking, "persons under a disability" must engage in the legal process by bringing proceedings by a next friend, or defending proceedings against them by a Guardian ad Litem.

6.4 The Official Solicitor only acts as next friend or Guardian ad Litem of last resort in that such intervention only occurs if there is no one else suitable, willing or able to act.

LAW GOVERNING MEDICAL TREATMENT AND WELFARE PROVISION

6.5 Article 69 of the Mental Health Order enables non-consensual treatment of detained patients, subject to Article 62 (2). Special protection operates in relation to certain forms of treatment:

(a) surgical operations which destroy brain tissue or the functioning of brain tissue (and operations for the surgical implantation of hormones for the purpose of reducing the male sex drive), which require a patient's consent except in cases of urgent treatment;

(b) electro-convulsive therapy (ECT) and the administration of medicine by any means once three months has elapsed from the first time the patient was given medicine for his or her mental disorder, which require either consent (from a person certified as capable of consenting) or a second opinion.

THE ISSUES

6.6 One of the main issues in mental health law is the question of capacity, which in this context relates to a person's ability to understand, to make decisions and to manage his or her affairs. It is closely related to mental disorder, including mental illness and learning disability.

6.7 Assumptions made about the capacity or incapacity of an individual can impact on people with a mental health difficulty or a learning disability and interfere in their right to make decisions in all aspects of their lives. This can include making decisions about, for example, what to do during the day, opening a bank account, entering into personal relationships, getting married or voting (as discussed in Chapter 4).

6.8 This fundamental aspect of a person's "human rights" is known as autonomy. Formal or informal perceptions of incapacity can result in the removal of autonomy Consequently the issue of capacity is central to a person's human rights.

6.9 From a human rights perspective, it does not inevitably follow that a person, including a child or a young person under 18, lacks capacity simply because he or she has some form of mental disorder. Moreover, the position is complicated by the fact that a person's "capacity" can vary according to the nature of the decision in question. Also, it should be remembered that a person's mental capacity will not necessarily remain static - this is known as intermittent capacity.

6.10 Under the ECHR, Articles 3, 5, 8 and 11 provide protection for a person's autonomy. Article 3 protects against inhuman or degrading treatment; Article 5 protects against arbitrary detention; Article 8 protects a person's private life, including his or her physical or mental integrity; and Article 10 enshrines a modified freedom of expression. Article 14 seeks to guarantee equal treatment and proscribes discrimination in relation to any of the above mentioned rights.

POTENTIAL CONCERNS

6.11 The potential human rights concerns in this area focus on the inappropriate removal of a person's autonomy, both in relation to a person with capacity and a person without capacity In broad terms, the issue to be addressed concerns the circumstances where a substitute decision-maker can validly make a decision on a person's behalf.

6.12 Substitute decision-making can potentially be contrary to human rights law in the following circumstances:

(a) in relation to a person who is acknowledged to have capacity;

(b) in relation to a person who is deemed incapable, but who actually has capacity; and

(c) inappropriate substitute decision-making in relation to a person who does not have capacity.

6.13 The Review's forthcoming report on proposed legislative reform deals extensively with these issues.

THE MENTAL CAPACITY ACT 2005

6.14 Mental health legislation has been undergoing reform throughout the United Kingdom. In April 2005, the Mental Capacity Act 2005 was enacted in England and Wales. The provisions of this legislation provide much greater protection for persons with mental disorder than the prevailing legislation in Northern Ireland. Moreover, the Act has adopted a number of principles established in common law and human rights law, which provide greater protection for persons with mental disorder.

HUMAN RIGHTS COMPLIANT LEGISLATION FOR NORTHERN IRELAND

6.15 Domestic legislation for children, young people and adults must be compliant with the Human Rights Act 1998 and in particular European Convention jurisprudence. The Review is addressing this issue in its work to develop a new legal framework.

Recommendation

12. Any new legal framework must include appropriate rules and procedures to govern:

(a) the determination of capacity or incapacity;

(b) the circumstances when substitute decision-making can be lawful in relation to someone who is capable;

(c) how to deal with persons with intermittent capacity; and

(d) the appropriate mechanisms for dealing with persons who do not have capacity, including putting in place sufficient safeguards to protect such persons.

CHAPTER 7

INVOLUNTARY DETENTION

THE ISSUES

7.1 The compulsory admission and detention of individuals in hospital constitutes an interference with their autonomy and liberty, and carries with it a risk of unlawful interference with their human rights. Considering whether to intervene in a person's life and involuntarily subject him or her to detention is often a complex and difficult task for the relevant authorities, which are charged with providing care and treatment, where appropriate. Moreover, the State has a duty to protect people from harm, including the person in question as well as others.

7.2 Liberty is a fundamental human right and the law safeguards individual autonomy. Involuntary detention raises a range of human rights concerns, including:

- when a person's mental state does not warrant detention;
- when a person's behaviour does not warrant detention;
- failure to observe procedural requirements and due process;
- continued detention when the legal criteria are no longer fulfilled;
- the need for adequate inpatient provision for children and young people and provision for the education of detained children and young persons; and
- the statutory role of relatives.

7.3 Decision-making in this area involves an assessment of the health of the person concerned and consideration of his or her rights and interests, as well as the interests of the wider community. There are a range of factors which must be taken into account when considering whether or not to intervene in a given situation. In every case, the State must be careful to act within the law, both prevailing domestic law and European Convention law.

DOMESTIC LAW

The Statutory Framework

7.4 The main statutory framework for the compulsory detention of individuals is Part II of the Mental Health (Northern Ireland) Order 1986 (MHO). Compulsory detention under this Order (sometimes called formal detention) comprises two stages:

- admission for assessment; and
- detention for treatment.

7.5 A person with a "mental disorder" can be compulsorily admitted to hospital for assessment. If he or she is living in the community, this process can be initiated by an approved social worker (ASW) or by the nearest relative on the recommendation of a medical practitioner. Part II of the Order also covers the detention of patients already receiving treatment voluntarily in a hospital.

7.6 A person can be admitted for assessment only if he or she is:

- suffering from mental disorder of a nature or degree which warrants his or her detention in a hospital for assessment (or for assessment followed by medical treatment); and

- failing to so detain him or her would create a substantial likelihood of serious physical harm to him or herself, or to other persons.

7.7 The Review, however, considers that the legislation is too narrow, in that, for example, the use of compulsory powers is entirely risk-based, with narrower criteria than elsewhere in the UK, thereby excluding some people with severely deteriorating conditions from care by disregarding psychological harm to others.

7.8 A nearest relative or, more often, an approved social worker, can make an application for a person to be admitted to hospital. The ASW is required by law to make an application for assessment in respect of a patient for whom he or she has responsibility, where he or she:

- is satisfied that such an application ought to be made; and

- is of the opinion, having regard to any wishes expressed by relatives of the patient or any other relevant circumstances, that it is necessary or proper for the application to be made.

7.9 The nearest relative can require the responsible authority to direct the responsible ASW to exercise this duty. If in these circumstances, theASW decides against making an application for assessment, he or she must inform the nearest relative of the reasons in writing.

7.10 The Review also has concerns that those with a personality disorder are excluded and recognises the importance that they receive treatment. A new legislative framework is required to ensure that people with a personality disorder are not excluded from accessing adequate treatment.

Application for Admission to Hospital by the Approved Social Worker

7.11 An application for assessment by an ASW will only be valid if he or she "has personally seen" the patient not more than two days before the date of the application. The ASW must consult with "the person appearing to be the nearest relative" before making an application, "unless it appears to the approved social worker that in the circumstances such consultation is not reasonably practicable or would involve unreasonable delay". If a patient is admitted to hospital following an ASW's application without such consultation, "it shall be the duty of that social worker to inform the nearest relative of the patient [of said admission] as soon as may be practicable".

Admission of Children and Young People

7.12 Children and young people can be detained under the MHO. The Code of Practice provides guidance to assist practitioners involved in this. Whenever admission of a child or young person to hospital is a possibility, the Code highlights three issues which should always be considered:

(a) what parent or guardian is legally responsible for the child, if any?

(b) is the child capable of making his or her own decision? and

(c) is the child subject to any court or other legal order?

Detention for Treatment

7.13 A patient may be detained for longer than 14 days only if his or her condition falls within the criteria contained in Article 12 (1) of the MHO, namely:

(a) the patient is suffering from a mental illness or severe mental impairment of a nature or degree which warrants his or her detention in hospital for medical treatment; and

(b) failure to detain the patient would create a substantial likelihood of serious physical harm to him or herself or to other persons.

7.14 A person can be initially detained for treatment for up to six months and can be further detained for a second period of up to six months. Thereafter, a patient can be detained for periods of up to one year. However, the MHO requires that once a person has been detained for a year, the authorisation of further detention must be made by two psychiatrists, of whom one must be "a person who is not on the staff of the hospital in which the patient is detained and who has not given either the medical recommendation on which the application for assessment in relation to the patient was founded or any medical report in relation to the patient under Article 9 or 12 (1)".

The Children (Northern Ireland) Order 1995

7.15 Provision is made under the Children (Northern Ireland) Order 1995 for interventions concerning children who require psychiatric care and treatment. A Supervision Order can be imposed where a child requires care which his or her parents are unable to provide. A court can authorise the psychiatric examination of a child subject to a Supervision Order if it is satisfied, on the evidence of a medical practitioner, that the child may be suffering from a mental condition that requires treatment and that is medically treatable. A court can also authorise the medical treatment of a child where appropriate. The child's consent is required under the Children Order.

Detention under the Health and Personal Social Services (Northern Ireland) Order 1972

7.16 The Health and Personal Social Services (Northern Ireland) Order 1972 makes provision for State intervention concerning persons who:

(a) suffer from grave chronic disease or, being aged, infirm or physically incapacitated, are living in insanitary conditions; and

(b) are unable to devote themselves, or to receive from persons with whom they reside, or from persons living nearby, proper care and attention.

Such intervention can include the non-consensual removal of such persons to other accommodation, where necessary, and subject to the safeguards prescribed, including having to apply to a Magistrate's Court for a removal Order.

7.17 A social worker (who may or may not be an ASW) may initiate proceedings to remove a person from his or her place of residence if he or she reasonably believes that removal is necessary in the interests of the person concerned, or to prevent serious nuisance or injury to a third party. The social worker must initially consult with both the person's general medical practitioner and a medical officer designated by the Health and Social Services Trust. He or she may make a removal application based on the medical certification of the Trust's designated medical officer that this is necessary.

7.18 Thereafter, the Trust may apply to the magistrates court within the jurisdiction where the person resides for an order to remove him or her to a suitable hospital or other place, and be detained there for up to three months. The Trust must give the person's nearest relative three days' notice of its intention to apply to the court for a removal order, and it must inform the person managing the accommodation which is to receive the person that a removal hearing is to take place. At the hearing, the Trust must lead evidence to substantiate its application. The court also may hear evidence from the person concerned and/or his or her nearest known relative. The person concerned has the right to be legally represented at such a hearing.

Non-Statutory Detention

7.19 Many people with mental health problems receive care and treatment outside the statutory framework, particularly elderly people cared for in hospital, nursing or residential care homes. Informal extra-statutory, non-consensual intervention (including deprivation of liberty) in the lives of such persons has traditionally been justified under the common law principle of necessity. Since the decision of the European Court in the Bournewood case (outlined below), however, such extra-statutory, informal interventions involving a deprivation of liberty may be unlawful.

RELEVANT HUMAN RIGHTS LAW: AN OVERVIEW

The Human Rights Act 1998

7.20 The Human Rights Act 1998 provides a mechanism whereby individuals who are aggrieved about a perceived breach of their rights under the European Convention on Human Rights may challenge the actions of the relevant public authority. This challenge can be by way of civil proceedings, a judicial review application, or by introducing the argument into other ongoing court or Tribunal proceedings. The Act has three important effects:

(a) courts must construe primary and secondary legislation in accordance with the Convention;

(b) public authorities have a duty to comply with the rights outlined in the Convention. A "victim" of a breach of that duty can challenge this in the courts; and

(c) the superior courts can make a finding that domestic law is incompatible with the Convention and can make a "declaration of incompatibility".

Article 5 (1)

7.21 The issue of detention of mentally disordered persons raises the prospect of a possible challenge to a public authority on the basis of a breach of Article 5 of the Convention (the right to liberty and security of person).

The Scope of the Right to Liberty

7.22 This right to liberty and security of the person is a qualified rather than an absolute right, and can be abrogated where liberty is restricted "in accordance with law" or where the circumstances outlined in sub-paragraphs (a) to (f) apply. Detention, therefore, which is carried out in accordance with the Mental Health (Northern Ireland) Order will prima facie not be in breach of Article 5. However, there is still considerable scope for a breach of Article 5 in the application of the legislation and, in some areas, aspects of the legislation may be incompatible with the Convention itself.

7.23 It is generally agreed that the core requirements of this Article are that a detention must take place in accordance with a procedure prescribed by law and that the detention must not be "arbitrary". This Article is also the central provision in relation to the penal detention of mentally disordered adults, and for those detained under "civil" powers.

Detention

7.24 The structure of the Article 5 protections for the liberty and security of the person are contingent on there having been "detention". If there is no detention, then the safeguards of Article 5 do not apply. Detention has been determined by factors such as duration, effect and the mode of restraint used.

On What Basis?

7.25 A pivotal factor in determining the legitimacy of a detention in the mental health context is a reliable finding of some mental disorder . The requirement outlined in Article 5 is a finding of "unsoundness of mind". No detailed interpretation of this concept has been developed by the European Court. This is consistent with that court's pragmatic approach to interpreting the Convention as a living instrument. The European Court has, however, held that Article 5 will not permit the detention of a person simply because his or her apparently irrational views or behaviour deviates from the norm in society.

7.26 The question of detention on the basis of 'severe mental impairment' was recently considered in a judicial review application by North and West Belfast Trust. The Mental Health Review Tribunal had held that the patient in question should be conditionally discharged as she was not suffering from "severe mental impairment" or "mental illness". Although this case raises issues relating to Article 5, these arguments were not examined by the Court, which ruled that "severe impairment of intelligence and social functioning" was a disjunctive test which required both proof of severe impairment of intelligence and proof of severe impairment of social functioning.

7.27 The European Court has previously addressed the issue of detention in *Winterwerp v The Netherlands,* where three minimum conditions were outlined for the detention of mentally disordered persons:

(a) there must be objective medical evidence such as to establish a true mental disorder;

(b) the mental disorder must be of a kind or degree warranting compulsory confinement; and

(c) the mental disorder must persist throughout the period of detention.

The Court acknowledged that different considerations might apply in "emergency" cases.

Bournewood and Informal "Admission"

7.28 The *Bournewood* case concerned the informal detention of persons without capacity to consent to detention. A 48 year old autistic man was admitted to hospital following a minor incident at a day care centre. He was compliant and made no attempt to leave. The House of Lords held that he was not detained and reversed a decision of the Court of Appeal, which had held that such patients could not be admitted informally.

7.29 The European Court found that the detention was a 'deprivation of liberty' pursuant to of Article 5 of the Convention. It also found that the detention was arbitrary and in contravention of Article 5 (1) because of the absence of procedural safeguards. The Court further found that there was a breach of Article 5 (4) in that there was not an available appropriate mechanism (such as a Mental Health Review Tribunal) to challenge the lawfulness of the detention: judicial review did not constitute an appropriate mechanism.

The Role of the Nearest Relative

7.30 Under the Mental Health Order, the nearest relative is afforded certain powers and rights in relation to the admission and detention of a patient. These powers raise issues under Article 5 and also Article 8 (the right to respect for private and family life) and were considered by the European Commission on Human Rights in *JT v United Kingdom.*

7.31 In that application, the detained person complained that the legislation did not include any formal mechanism whereby she could alter the identity of her nearest relative. The applicant complained that she did not want the nominated person to be her "nearest relative" and objected to this person being given confidential medical information. This case was settled on the basis that legislation would be introduced to permit reasonable objections to the nearest relative.

7.32 The Review agrees with the recommendation in the Human Rights Commission's report, "Connecting Mental Health and Human Rights" that the role of the nearest relative in relation to the compulsory detention of individuals should be discontinued.

Provision of Treatment

7.33 In *Aerts v Belgium,* the European Court held that where the applicant had not been provided with any treatment for the condition which had given rise to his detention then there was a breach of Article 5 (1) (e). The applicant was detained in a psychiatric prison wing rather than a social protection centre. The Court held that as he had not been convicted of any criminal offence his detention could not be justified under Article 5 (1) (a). The only possible justification for his continued incarceration was Article 5 (1) (e).

7.34 The Court found that there must be some relationship between the ground of permitted detention and the location and conditions of that detention and, in principle, Article 5 (1) (e) detention could only be justified if the patient was held in an appropriately therapeutic setting.

Lack of Adequate Resources

7.35 The European Court has considered the Article 5 implications of continued detention in circumstances where an individual would be released, but for a lack of adequate treatment resources. In *Johnson v United Kingdom,* it found that where lack of placement facilities resulted in indefinite detention, this could constitute a breach of Article 5 (1) (e). The applicant had been found not to be suffering from any mental disorder and his conditional discharge was deferred pending the provision of suitable hostel accommodation.

Article 5 (4)

7.36 This Article introduces due process mechanisms which provide procedural support for the substantive Article 5 right to liberty. It is important to note that the protections of Article 6 may also be applicable in relation to detention in the mental health sphere. This article raises four discrete issues:

(a) a review of the lawfulness of detention;

(b) by a court;

(c) in a reasonably prompt manner; and

(d) with the power to release persons who are unlawfully detained.

7.37 Review in the mental health context must be periodic, because the lawfulness of the detention is contingent on the persistence of the illness. Excessive delay in the conduct of periodic review will be in breach of Article 5 (4).

Recall of Patients Conditionally Discharged

7.38 The Secretary of State has the power under Article 48 of the MHO to recall a person who has been discharged subject to a Restriction Order. There is no requirement for a further medical assessment prior to the exercise of this power. Some commentators have noted in relation to the English legislation, that "it is difficult to see how this power is compatible with the Convention". Where a restricted patient is re-admitted for assessment or treatment, there is no mechanism for application to the Mental Health Review Tribunal unless the formal power under Article 48 (3) has been used. This anomaly is also likely to be in breach of Article 5 (4) of the ECHR.

Minors and Detention: Article 5 (1) (d)

7.39 The Review considered the human rights and equality issues concerning children and young people who are detained in the context of mental ill-health. Recommendations on this issue in the Review's report on child and adolescent mental health services are informed by human rights and equality principles.

7.40 The European Convention envisages that detention of a minor will be lawful where it is done for the purposes of educational supervision. There is a clear tension between the terms of Article 5 (1) (d) and the use of accommodation orders under the Children (Secure Accommodation) Regulations 1995.

7.41 The European Court has taken a relatively broad view of the term 'educational supervision'. In *Koniarska v United Kingdom,* the Court found that "the words 'educational supervision' must not be equated rigidly with notions of classroom teaching. In particular, in the present context of a young person in local authority care, education supervision must embrace many aspects of the exercise, by the local authority, of parental rights for the benefit and protection of the person concerned."

7.42 In *DG v Ireland,* the European Court found that educational supervision could apply beyond the statutory school leaving age. The applicant was a 17 year old who displayed indications of a serious personality disorder. There was no secure unit available for his assessment in the jurisdiction and he was consequently detained in a penal facility. The

Court found that the absence of any instruction, education or recreational facilities at the penal institution constituted a breach of Article 5 (1) (d).

7.43 It would appear, therefore, that detention in inappropriate facilities can constitute a breach of Article 5. Given the absence of appropriate facilities for mentally disordered young people in Northern Ireland, this is likely to be a continuing problem in relation to the detention and treatment of minors here. (Chapter 5 summarises the Review's conclusions on deprivation of liberty and the right to education.)

CONCLUSIONS

7.44 The following constitute the Review's conclusions on these issues:

- a new definition of mental disorder is needed;
- the criteria for detention should include the protection of other persons from significant risk of serious harm, and there should be adequate safeguards put in place to prevent misuse and abuse of such a power. At the same time, the Review recognises the concerns that broadening the definition may affect a person's right to liberty. To ensure that appropriate safeguards are put in place, there should be detailed guidance in a Code of Practice in relation to such an amendment;
- there is concern over the role of the nearest relative: the Review considers this
- current role in relation to compulsory detention should end;
- statutory authorities should provide information to and consult with the patient's "named" or nominated person rather than the nearest relative;
- proper safeguards must be included to ensure that patient needs are properly accommodated: in particular, to properly protect children;
- there is concern over the adequacy of resource allocation to meet the needs, including the educational needs, of compulsorily detained children;
- if children are to be subject to detention, suitable and adequate resources should be available to protect their rights and best interests, including their educational needs and rights;
- there should be appropriate provision so that the disparate needs of diverse individuals and groups are adequately accommodated;
- potentially the anti-stigmatisation provision at Article 10 of the MHO should be strengthened to protect assessed and detained persons from post-detention discrimination; and
- the needs of people with severe personality disorder in relation to compulsory detention must be fully addressed.

Recommendations

13. The definition of mental disorder should be reviewed.

14. The criteria for detention should be broadened to include the protection of others from significant risk of serious harm, with appropriate safeguards put in place to prevent misuse or abuse of this power.

15. The role of the nearest relative as applicant in the compulsory detention of patients should end.

16. There should be appropriate safeguards defined in legislation for "Bournewood detentions", in accordance with the European Court's ruling.

17. Proper safeguards should be put in place to ensure that patient needs are properly accommodated, particularly as regards children and young people, in accordance with the principle of reciprocity of rights.

18. Given the previous under-funding of services for children and young people, there must be adequate resources made available, including the provision of age-appropriate services and facilities, to protect the rights, needs and best interests of compulsorily detained children and young people, including their educational needs and rights.

19. The anti-stigmatisation provisions in the present legislation must be built upon to protect assessed and detained persons from post-detention discrimination.

CHAPTER 8

REPRESENTATION AT MENTAL HEALTH REVIEW TRIBUNALS

THE ISSUES

8.1 One important human rights issue is the extent to which the law currently safeguards a patient's right to have his or her case properly aired before a Tribunal, a crucial dimension of a person's access to justice.

8.2 In cases before courts and tribunals, parties commonly retain lawyers and provide them with instructions as to their situation. On the basis of these instructions, the lawyer then presents the client's case to the court or Tribunal.

8.3 Persons with mental health difficulties or a learning disability may be potentially disadvantaged by reason of a reduced ability to make appropriate decisions in relation to representation, and/or by a reduced ability to provide coherent, rational and comprehensible instructions. In such circumstances, the human rights and equality issues for consideration are, what provision:

(a) does the law make to alleviate/prevent disadvantage and prejudice to the person concerned?

(b) should the law make to alleviate/prevent disadvantage and prejudice to the person concerned?

THE LEGAL BACKDROP

8.4 In the case of *Megyeri v Germany* (1993), Mr Megyeri was convicted of a number of criminal offences. The European Court ordered that he be detained in a psychiatric hospital. Although his detention was reviewed periodically, in two sets of review proceedings he did not ask for representation and the review body did not appoint a lawyer to assist him. He claimed that this failure to appoint a lawyer contravened Article 5 (4) of the ECHR.

8.5 The European Court found that the absence of representation in his case constituted a breach of Article 5 (4): that the national authorities should have ensured that he was legally represented at all hearings.

8.6 European Convention Law does not appear to guarantee a right to legal representation in every case. However, the implications of the *Megyeri* decision appear to be that:

"even if a right to representation funded by the State is not (yet) a general right, a court which reviews detention must always consider whether a particular person is capable of acting for himself, for example, whether he is able to marshal arguments and points in his favour, and understand any legal issues arising. If not, then legal representation must be provided and must be paid for by the State."

8.7 In Northern Ireland, the Mental Health Review Tribunal (Northern Ireland) Rules 1986 do not guarantee a patient legal representation. Rule 10 (1) permits a patient to authorise any person to act for him or her as long as the nominee is not *"a person liable to be detained or subject to guardianship under the Order or a person receiving treatment for mental disorder at the same hospital as the patient"*.

8.8 Where the patient does not want to conduct his or her own case and has not authorised a representative to act for him or her, the Tribunal may appoint a representative to act (Rule 10 (3)). This apparently was originally intended by the legislator to be a discretionary power. Notwithstanding, pursuant to the Human Rights Act 1998, the Mental Health Review Tribunal should interpret and apply the Mental Health Review Tribunal (Northern Ireland) Rules 1986 in light of the *Megyeri* decision.

PREVALENT CONCERNS

8.9 A number of concerns in relation to compulsorily detained mentally ill patients and their access to justice (and, in particular, liberty) can be identified. Specifically, how many such patients are able to organise their thoughts sufficiently coherently to enable them to "marshal arguments and points in [their] favour and understand any legal issues arising"? More specifically, how many patients are able to make considered decisions in relation to representational issues, such as:

- the arguments they want to put forward;
- whether they ought to appear in person or obtain representation; and
- whether it is in their interests to obtain legal representation?

POTENTIAL PROBLEMS IN RELATION TO PATIENT REPRESENTATION

8.10 Mental Health Review Tribunal hearings focus on a patient's “right” to liberty and, in particular, the statutory criteria governing compulsory detention. The subject matter of these hearings ranks high in legal terms given the importance attached by the law to individual liberty. Such hearings are often contentious by reason of the conflicting views of the Health and Social Services Trust and the patient. It is fundamental to both a patient's health and welfare and his or her human rights that he or she is properly represented at these Tribunals.

8.11 From a patient perspective, there are arguably a number of shortcomings in the current system of representation at Mental Health Review Tribunals, creating obstacles which can serve to abrogate his or her human rights (eg. the right to liberty and/or a fair hearing) including:

- no automatic access to legal advice and assistance. Often decisions in relation to representation are left in the hands of the patient, who is not always fully capable of acting in his/her best interests, by reason of, inter alia, the medical condition and/or medication;

- some patients seek legal assistance and obtain non-expert assistance. For example, junior barristers and junior and/or generalist solicitors are often involved in representation notwithstanding their lack of the requisite knowledge, skill, experience and/or expertise; and

- some patients refuse legal assistance and represent themselves or obtain non-legal representation. This can detrimentally affect their prospects of having their arguments and submissions properly presented and fully aired.

8.12 Such factors undermine a patient's right to have his or her case properly presented to a Tribunal, which, in turn, can abrogate a patient's human rights, including the important right to liberty.

COMPETING RIGHTS, INTERESTS AND OBLIGATIONS

8.13 All of the above issues concern the interplay between a patient's interests, a patient's rights and the responsibility of the State. Two of the main underlying ethical issues are:

- in what circumstances should a patient's rights outweigh his or her perceived best interests? (eg, if the patient refuses to nominate a representative or instruct a representative who has been appointed to act on his behalf, should the patient be entitled to dispense with representation and, if so, when?); and

- what policies, procedures and practices should the State put into place to ensure a patient's access to justice and the patient's right to have his or her case properly aired? (eg, should the State ensure that every patient receives legal representation, or that legal representation is always provided in specified circumstances?).

CONCLUSIONS

8.14 The Review reached the following conclusions:

- a patient should have an entitlement to expert legal representation at a Mental Health Review Tribunal;

- such representation should be provided by experienced lawyers with an expertise in the area of mental health and compulsory detention. There are different models of specialist legal provision, including a publicly-funded specialist who might operate out of a law centre, and a specialist and accredited panel of practising lawyers;

- such provision should be available to all, irrespective of a person's income or savings;

- there may be situations where it would also be useful for a patient advocate to play a role in assisting the patient;

- as a general rule, a patient should be able to represent him or herself, or appoint a representative of his or her choice to represent him or her;

- there may be circumstances where the requirements of justice (including the patient's right to a fair hearing) demand that a suitable lawyer is appointed to act on the patient's behalf, whether or not the patient consents to such a course; and

- in relation to children, dual or tandem representation should be considered, wherein a lawyer and a Guardian ad Litem would be appointed to act for the child. Such a tandem approach will ensure that proper representations are made to the decision-making body on both the child's rights and best interests.

Recommendations

20. A patient, irrespective of his or her income or savings, should have an entitlement to expert legal representation at an independent Tribunal, provided by experienced lawyers with expertise in mental health and compulsory detention.

21. A patient should be able represent him or herself and/or appoint a representative of his or her choice for this purpose. Where appropriate, a patient advocate may play a role in assisting the patient.

22. Where the requirements of justice demand it (including the patient's rights to a fair hearing), a suitable lawyer should be appointed to act on the patient's behalf, whether or not the patient consents to such a course.

23. In relation to children, dual or tandem representation should be considered, whereby a lawyer and a Guardian ad Litem would be appointed to act for the child.

CHAPTER 9

ADVOCACY

INTRODUCTION

9.1 People with a mental health problem or a learning disability are particularly vulnerable to human rights violation. Their rights and interests must be identified specifically under the legislation and within regional policy mandates. For human rights to be a realitythey must be accompanied by accessible and effective enforcement mechanisms.

9.2 Advocacy seeks to support individuals to express and have their views heard. It aims to redress any imbalance of power between the individual and professional. It is concerned with empowerment, autonomy and self-determination, the safeguarding of citizenship rights and the inclusion of otherwise marginalised people.

9.3 There are a range of different approaches to providing advocacy, including:

- identifying someone to represent the interests of another individual, or to support an individual to represent him or herself;
- the provision of independent information and advice about rights and services; or
- supporting people to come together as a group to have a greater say in the issues which concern them and to bring about change.

RELEVANT HUMAN RIGHTS AND EQUALITY LAWS AND STANDARDS

9.4 The main human rights and equality laws and standards applicable to advocacy are:

- the European Convention on Human Rights 1950;
- the Disability Discrimination Act 1995;
- the Northern Ireland Act 1998 (Section 75);
- the Race Relations (Northern Ireland) Order 1997;
- the Children (Northern Ireland) Order 1995;
- the Mental Health (Northern Ireland) Order 1986;
- the UN Convention on the Rights of the Child 1989;
- the UN Declaration of the Rights of Mentally Retarded Persons 1971; and
- Standard Rules on the Equalisation of Opportunities of Persons with Disabilities.

THE NEED FOR ADVOCACY

9.5 The ECHR is intended to guarantee not rights that are theoretical and illusory, but rights that are practical and effective.

9.6 Article 6 guarantees everyone the right to a fair hearing. Article 5 guarantees everyone the right to liberty and security of a person and Article 8 guarantees everyone the right to family and private life.

9.7 Articles 1 and 14 provide a duty to guarantee effective rights to everyone without discrimination. Strasbourg jurisprudence has been highly influential in the development of both the substantive and the procedural aspects of the rights of those subject to compulsion. The European Court's emphasis on procedural aspects of Convention rights has extended its scope and is of great practical significance in the field of compulsion under mental health law. In the case of children, it acknowledges the requirement for special consideration for young people in detention and supports the need to have the lawfulness of detention reviewed in compliance with Article 37 (b) of the UNCRC.

9.8 Different types of advocacy may be needed by different people at different times of their lives and to respond to different circumstances. Children, older people, people from diverse ethnic communities, individuals with complex, profound and multiple disabilities and people involved with forensic services are likely to need additional, specific support to address their needs.

9.9 Advocacy services are unevenly and poorly developed in Northern Ireland. The recently articulated and increasing demand for advocacy support is an indication of the need to promote and support the rights of people with a mental health problem or with a learning disability. A range of different models of advocacy has developed in response to accepted needs in the rest of Europe and internationally.

9.10 Health and social care staff and relatives often act as advocates for individuals with mental health problems or a learning disability. However, the possibility of conflict of interest has increased the demand for independent advocacy services to ensure that the voice and interests of the individual are heard.

9.11 Carers, too, may need separate advocacy services, to support them in accessing independent information and in expressing their views about their own distinct needs. Advocacy services can also support carers in their role as advocates for the person they care for.

9.12 It is important that people with mental health problems or a learning disability can choose if they want to use an advocacy service, and be able to choose the model of advocacy support that best suits their preferences and needs. Carers should also be offered choice in advocacy support.

9.13 Particular consideration must be given to the principles, procedures and models of advocacy available to individuals who may not be able to exercise this choice, to ensure that they enjoy equality of opportunity and are not disadvantaged.

ISSUES EXAMINED

9.14 The particular issues examined were:

- the need for advocacy;
- the human rights principles involved;
- models of advocacy;
- advocacy in other jurisdictions;
- advocacy support for:
    - people with mental health problems;
    - people with a learning disability;
    - people with a learning disability who have experienced mental health problems; and
    - the distinct needs of vulnerable groups including children, older people, people from diverse ethnic communities, individuals with profound and multiple disabilities and people involved with the criminal justice system.

9.15 In addition to the papers and presentations made at meetings, a seminar on advocacy was held for the Review members.

CONCLUSIONS

9.16 The consensus was that there should be clear provisions within a legislative and policy framework to enable people with mental health problems or a learning disability:

- to understand the proceedings in which they are involved; and
- to participate in their ongoing care and the accompanying decision-making process, to the greatest extent possible.

9.17 The objective should be to have in place:

- a range of independent advocacy support services delivered by a range of providers;

- support for people with mental health difficulties or a learning disability in exercising their rights;
- services which are compliant with all legal requirements in Northern Ireland;
- a coherent, co-ordinated, regional strategic framework which will provide people with mental health difficulties or a learning disability with access to advocacy support;
- an advocacy support service which is available both in hospital and in community settings;
- advocacy support services that will extend to those undergoing assessment and treatment voluntarily and involuntarily and which will reflect the diverse needs of people with mental health difficulties or a learning disability;
- advocacy support services which will pay particular attention to the circumstances where the autonomy and self-determination of individuals may be restricted or denied.

9.18 A strategy to achieve these objectives should be developed with the involvement of all stakeholders, including users, carers and families and should:

- set explicit deadlines and targets for implementation;
- ensure the development of agreed quality standards and consistent monitoring of advocacy support; and
- work in tandem with other current and forthcoming strategies such as the children and young people's strategy and the carers' strategy.

Recommendations

24. There should be a statutory right to independent advocacy support, embracing a range of different models.

25. There should be a regional strategy for the development and funding of independent advocacy support in Northern Ireland. This will involve a number of Northern Ireland Departments and should be co-ordinated by the Department of Health, Social Services and Public Safety.

CHAPTER 10

CONCLUSION

From its outset, the Bamford Review placed respect for human rights and equality of opportunity at the heart of its work and its vision for the reform and modernisation of services. As this report stresses, this is not an optional extra, it is a legislative imperative.

This report has considered a number of situations where actual or potential human rights and/or equality issues arise in relation to people with a mental health problem or a learning disability; and has made recommendations to address these scenarios. We recognise that there may well be others which we have not examined.

Implementing these recommendations is the responsibility of the Government and public bodies, and to achieve the Review's person-centred and rights-based vision for services and opportunities will require co-ordinated action across Government and by these public bodies, responding to the particular needs of different groups. Importantly, also, it will require additional resources, which should be allocated and spent in accordance with equality and human rights principles.

This is not only the challenge of this report, but of the entire Bamford Review.

ANNEXES

Annex 1

MEMBERSHIP OF THE HUMAN RIGHTS AND EQUALITY SUB GROUP

Lady Christine Eames (Chair)	Human Rights Commission
Ms Tara Caul	Children's Law Centre
Miss Brenda Donnelly	Royal Courts of Justice
Mr Bill Halliday	Equality Commission; now Praxis Care Group
Dr Raman Kapur	Threshold
Dr Caroline Marriott	North and West Belfast Trust
Ms Patricia Monaghan	LAMP
Dr May McCann	CAUSE (and a Carer)
Miss Jane McConnell	Royal Courts of Justice
Miss Joanne McDonald	Strule Buzz Group
Professor Tony McGleenan	University of Ulster
Mr Paddy McGowan	Irish Advocacy Network
Dr Paschal McKeown	Mencap and LEAD (the Northern Ireland Coalition on Learning Disability)
Dr Angela O'Rawe	Queen's University
Mr Michael Potter	Royal Courts of Justice
Mr Sean Ferrin) Mr Roy Keenan)	Secretariat

Annex 2

RECOMMENDATIONS

Access to Rights

1. The Government and the Commissioners for Human Rights, Children and Equality must actively promote the rights of people with mental health difficulties and people with a learning disability and provide accessible information about these rights to them.

2. Public, voluntary and independent sector staff, including front line staff and policy makers, must receive training on human rights and equality issues in relation to people with a mental health problem or a learning disability. This requirement must be reflected in contractual arrangements.

3. Mental health and learning disability services must reflect and be sensitive to the different religious, ethnic, racial and cultural backgrounds of people and groups in Northern Ireland. Services must comply with the equality obligations of Section 75 of the Northern Ireland Act 1998 and take account of those who experience multiple disadvantage.

4. Government and public bodies must ensure that people with mental health difficulties or learning disability have equal access to the same range of services and opportunities as other people in Northern Ireland.

5. Government and public bodies must actively address issues of stigma and prejudice and implement action plans for this purpose.

6. Government and public bodies must address the inequalities experienced by carers and uphold their right to have their needs recognised and met. Carers must have their expertise recognised and respected and be fully involved as equal partners in the planning and delivery of services.

Right to Vote, to Found a Family and to Life

7. Legislation dealing with capacity should be based on the presumption of an individual's ability to make a decision. Responsibility should be placed on those challenging or questioning a person's decision-making capacity to provide evidence of incapacity.

8. The continued use of common law in current electoral practice should be reviewed as a matter of urgency.

9. Government and public bodies should provide training and information to their staff to enable them to comply with the positive duty to protect everyone's right to life.

Education Rights

10. The right of every child and young person with a mental health problem or a learning disability to education should be explicitly recognised and reflected in any new legislative framework.

11. The Government must ensure that people with mental health difficulties or a learning disability have equal access to lifelong learning opportunities. This includes the funding and development of specific programmes and additional support, where needed.

Capacity, Incapacity and Human Rights

12. Any new legal framework must include appropriate rules and procedures to govern:

    (a) the determination of capacity or incapacity;

    (b) the circumstances when substitute decision-making can be lawful in relation to someone who is capable;

    (c) how to deal with persons with intermittent capacity; and

    (d) the appropriate mechanisms for dealing with persons who do not have capacity, including putting in place sufficient safeguards to protect such persons.

Involuntary Detention

13. The definition of mental disorder should be reviewed.

14. The criteria for detention should be broadened to include the protection of others from significant risk of serious harm, with appropriate safeguards put in place to prevent misuse or abuse of this power.

15. The role of the nearest relative as applicant in the compulsory detention of patients should end.

16. There should be appropriate safeguards defined in legislation for "Bournewood detentions," in accordance with the European Court's ruling.

17. Proper safeguards should be put in place to ensure that patient needs are properly accommodated, particularly as regards children and young people, in accordance with the principle of reciprocity of rights.

18. Given the previous under-funding of services for children and young people, there must be adequate resources made available, including the provision of age-appropriate services and facilities, to protect the rights, needs and best interests of compulsorily detained children and young people, including their educational needs and rights.

19. The anti-stigmatisation provisions in the present legislation must be built upon to protect assessed and detained persons from post-detention discrimination.

Representation at Mental Health Review Tribunals

20. A patient, irrespective of his or her income or savings, should have an entitlement to expert legal representation at an independent Tribunal, provided by experienced lawyers with expertise in mental health and compulsory detention.

21. A patient should be able to represent him or herself and/or appoint a representative of his or her choice for this purpose. Where appropriate, a patient advocate may play a role in assisting the patient.

22. Where the requirements of justice demand it (including the patient's rights to a fair hearing), a suitable lawyer should be appointed to act on the patient's behalf, whether or not the patient consents to such a course.

23. In relation to children, dual or tandem representation should be considered, whereby a lawyer and a Guardian ad Litem would be appointed to act for the child.

Advocacy

24. There should be a statutory right to independent advocacy support, embracing a range of different models.

25. There should be a regional strategy for the development and funding of independent advocacy support in Northern Ireland. This will involve a number of Northern Ireland Departments and should be co-ordinated by the Department of Health, Social Services and Public Safety.

THE BAMFORD REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY
(NORTHERN IRELAND)

LIVING FULLER LIVES

June 2007

CONTENTS

ANNEXES

FOREWORD

The Bamford Review of Mental Health and Learning Disability (Northern Ireland) consists of a number of interlinked reviews under one overarching title, and encompasses policy, services and legislation.

In consultation with Government, we have agreed to produce our reports separately in a phased manner.

This further report deals with dementia and the mental health issues of older people, and is the last of the Review's "service provision" reports.

In common with the other reports we have produced, this report reflects the evidence-based approach we have adopted to our task and the invaluable contribution of service users, their carers and families. This committee, for example, conducted a wide-ranging stakeholder consultation as part of its initial fact-finding work.

I thank Nevin Ringland, his committee and all who contributed to the production of this report, and I commend it to you.

Roy J McClelland (Professor)
Chairman

May 2007

PREFACE

CULTURE OF CARE

In undertaking this Review, we have asked ourselves a number of questions. Firstly, what do we want? We want the kind of health and social care we would like for ourselves. It would be tailored to our individual histories and circumstances. It would be given by a dedicated person or small group of people with enough time. They would be available to us and our carers at all times. Staff would be skilled in understanding and meeting our needs. They would be well supported to deal with our emotional pain. The help offered would be imaginative and start from the view that problems can be solved. It would allow us to be ourselves and to retain as much of our daily lives and routines that we want. **It is in the fine grain of care that quality is really experienced, the tiny details that show that our uniqueness has been recognised.**

This vision is highly problematic in an ageist society which also stereotypes people with dementia/ mental illness. The fact that society in the 21st century is ever more risk-averse adds another layer of difficulty, in that staff may be under more pressure to protect rather than to enable.

The next question is whether the vision is achievable. Some of the examples of best practice described to the Review showed that this vision of health and social care is possible, although the degree of effort required at all levels of the organisation was quite exceptional.

The third question then is, how can the best practice the Review has seen become the norm and be sustained over time?

Organisations, especially public services, operate in a society with values and an ageist society will tend to have ageist organisations. The Review itself should make a contribution to changing these attitudes, in part by drawing attention to them, in part by providing information about the wishes and potential of older people with dementia and functional mental illnesses and their carers.

The culture of care in any organisation starts at the top. Remarkable individuals and teams do emerge, but they are rarely able to sustain the quality of their care over time unless the organisation is fully supportive. Ideally we need what Senge (1990) calls a "learning organisation":

"…. organisations where people continually expand their capacity to create the results they truly desire, where new and expansive patterns of thinking are nurtured, where collective aspiration is set free and where people are continually learning to see the whole together."

This is a useful concept in the fields of health and social care for people with dementia and functional mental illnesses because these are fields which are very dynamic at the moment. Attitudes, knowledge, skills and expectations are changing all the time as we learn what people need and what they are capable of. There are increasing amounts of research in all aspects, such as medication, communication, therapeutic interventions and user views.

There is also a great deal of innovative practice, which is constantly identifying needs and exploring new responses, thereby raising expectations. Knowledge and skill does not usually, or even, often, reside only at the top of organisations. Users, carers and staff at all levels need to learn together about what can be achieved and how to achieve it. Traditional approaches such as training are now seen as only a small part of the process of culture change.

The Review is itself a demonstration of how a learning organisation can work in that all parties have learned from each other.

Professor Mary Marshall

INTRODUCTION

Background to the Review

A Review of the policy, practice and legislation relating to mental health and learning disability and including dementia and mental health issues of older people was commissioned by the Department of Health, Social Services and Public Safety (DHSSPS) in October 2002. The impetus for establishing the Review included:

- recent reviews of mental health legislation in neighbouring jurisdictions;
- the need to ensure that law, policy and practice is in keeping with human rights and equality legislation; and
- the need to reflect current evidence of best practice.

The Review is managed by an overall Steering Committee which has delegated specific areas to ten Expert Working Committees. This Report summarises the findings and recommendations of the Dementia and Mental Health Issues of Older People Working Committee, whose membership can be found in Annex 1.

Key Purposes of the Dementia and Mental Health Issues of Older People Review

The primary aim of the Review is to provide a vision of what mainstream and specialist health and social care services for older people with dementia and functional mental illnesses should look like and how they should work together to ensure that service users and carers have their needs met irrespective of where they are in the system, without encountering discrimination or barriers to access.

In order to achieve this, the Review focused on:

i. specific models of care and standards of provision in relation to the quality, comprehensiveness, effectiveness, accessibility and acceptability of provision;

ii. detailed consideration of community/ primary, specialist and secondary care services and the interfaces between them; the interface between health and social care and links with other sectors such as housing; the complementary roles of statutory and independent services and the issues surrounding multi-disciplinary and multi-agency working; and

iii. the strategies, systems, processes and resources which need to be in place to ensure that the recommendations made in the Report can be realised.

Service Users and Carers

The work included an extensive public consultation exercise involving service users, carers and service providers. This was facilitated by the Rural College and carried out in February and March 2005. Sixteen meetings took place at a range of venues across Northern Ireland, with a total of 294 people attending. This Report draws heavily on the views expressed by stakeholders at these meetings. There was also carer representation on the Working Committee.

It is also interesting to note, that of the 25 Working Committee members, approximately 90% have close relatives who have dementia and/or mental health problems. While this does not replace carer and user representation, it has brought an additional perspective and perhaps a greater sense of energy to the work.

Interface Issues

The Review acknowledges the need for this Report to be considered in conjunction with a number of its other Reports, particularly where there are clear interface issues. Some examples of these are:

- Adult Mental Health Services – Community based services for older people with Dementia and Functional Mental Illness (FMI) are sometimes managed within the Mental Health Programme of Care, sometimes by Elderly Services Programmes and sometimes split between both. There are also clear interface issues in terms of arrangements for those older people with enduring or episodic severe mental disorder who have reached the age of 65 and younger people who develop dementia.

- Learning Disability – The increasing number of adults with a learning disability who are living into old age has obvious implications in terms of prevalence rates for dementia, depression and other functional mental illnesses. People with Down's Syndrome in particular are at high risk of developing Alzheimer's Disease as they grow older. There are clear interface issues in terms of enabling older people with a learning disability to access mainstream dementia services. Joint working arrangements are also likely to become more commonplace.

- Legislation – There are many legal issues affecting older people with Dementia and Functional Mental Illness, for example consent and capacity, compulsory admission for assessment and treatment, management of financial affairs, issuing of advanced directives. Current legislative provision is often deemed to be inadequate in terms of the care and protection it affords to older people with dementia or severe mental health needs.

- Alcohol and Substance Misuse – The increasing numbers of older people drinking beyond recommended levels (3% in 1986 to 7% in 2003, NISRA) is likely to see accompanying increases in Alcohol Related Brain Damage (ARBD). People with ARBD typically present with complex physical, social and emotional needs which require a co-ordinated approach across health and social care professions and a range of agencies, such as housing, social security and, often, criminal justice.

- Mental Health Promotion – The Review's report "Mental Health Improvement and Well-Being – A Personal, Public and Political Issue" acknowledges that the prevalence of mental health disorders is relatively high in later life, with about a third of all admissions to psychiatric care and referrals to community mental health services involving people over the age of 65. Depressive symptoms affect 10-15% of those aged 65 and over (Psych. Bulletin 2003). Older people also have a higher risk of completed suicide than any other age group worldwide (WHO, 2002).

A range of preventative strategies is required, both to promote good mental health in older age and to reduce risks (where there are identifiable risk factors) of developing dementia.

CHAPTER 1

VISION, PRINCIPLES AND POLICY

1.1 The Review has provided a unique opportunity to address the full spectrum of issues relating to dementia and mental health issues of older people. This Report provides the blueprint: a blueprint that is as dependent on cultural change as much as on an investment of new resources. This incorporates a new sense of partnership and equality of esteem for service users, a valuing of carers as equal partners in service provision and effective team-working and collaboration within and between service provider groups.

Where We Have Come From

1.2 Over the past thirty years, successive local and national strategies and a growing body of research evidence have advocated refocusing of service provision away from hospital settings towards community based provision. This shift reflects the preference of service users for home life over institutional care (Allen et al. 1992) for local services over distant ones, for services sensitive to community needs and the pursuit of normalisation and integration for those who would formerly have been segregated and excluded in institutional care settings. This has led to an increased emphasis on the provision of more and better care in the community, embracing support for primary care services and the development of a spectrum of community based facilities and services. Alongside this has been an increasing commitment to the participation of service users and carers as partners in the planning, development, delivery and evaluation of services.

Where We Are Now

Management Structures

1.3 There is no agreed management structure for the planning and delivery of services to older people with mental health issues. The Dementia Policy Scrutiny 1994 recommended that responsibility for dementia services should be in Elderly Care Programmes. Subsequently, Boards and Trusts have organised services in a variety of ways. Some have developed integrated Mental Health Services for Older People teams, some located in elderly care and some in mental health. Other services have developed separate teams for dementia and functional mental illness (FMI), sometimes located in one programme of care (POC) and sometimes split between these POCs, both at Trust and Board level. As a consequence of different recoding systems being in place or even none in place, there has not been a comprehensive picture of the needs of these client groups. In addition, there has not been an overall mapping of many instances of best practice which do exist around Northern Ireland. Funding for dementia comes through the Elderly POC and for FMI through Mental Health, together with funding for General Adult Mental Health Services. There is no separate planning or funding for FMI in older people.

1.4 Older people with mental health problems have not historically been clearly identified as a service user group by commissioners (Finch, 2004). Commissioning arrangements have consequently tended to be unco-ordinated and fragmented, leading to poor outcomes for older people with mental health issues. A number of inspections by the Social Services Inspectorate between 2002–2003 (DoH, 2003) found that there was also a frequent lack of clear transitional arrangements and of organisational coherence between mental health and older people's services.

1.5 The absence of any performance management of the Dementia Policy Scrutiny recommendations, has required the Review to consider, as part of its agenda, the issue of where mental health services for older people should sit.

1.6 There was a mixed response in the public consultation to this question, although the majority were supportive of the view that this provision should be the responsibility of a specialist multi-disciplinary team. Carers were generally of the view that proper resourcing of appropriate specialist services was the key consideration, rather than which programme services were aligned to.

1.7 The Review has considered this issue in some depth and can see advantages and disadvantages to having the service located in either the Mental Health or the Elderly Programme of Care. We believe, however, that there are definite disadvantages to having it split between both.

1.8 The Review's position is that while mental health services for older people can sit within either the older people's or mental health POC (there being clear evidence of services working well within both contexts) they should be provided as a discrete sub-speciality, with ring-fencing of money and specialism. There should also be a single, defined commissioning service, with clear protocols in place for interfacing with other programmes of care. It is essential that users and carers are integrally involved in the commissioning process.

1.9 The Review is mindful that traditional structures within Boards and Trusts are changing as a result of the Review of Public Administration. With increasing numbers of older people and increasing stress on health and social services, there is an awareness that traditional services for older people will need to change. Generally there is a move towards whole system planning. This would involve fundamental changes in primary, community and secondary care and should include mental health services for older people. Dementia and severe FMI are chronic, complex conditions and would fit well within a chronic disease management model such as is currently beginning to be used for conditions such as diabetes or chronic obstructive airways disease

1.10 In Great Britain, some services for this population have developed further to form Care of Elderly People Programmes, e.g. in Nottingham and Newcastle, where Mental Health of the Elderly and Geriatric Medicine are merged under the one management umbrella. Also, In England, the National Service Framework for Older People initiative is now piloting the development of complex community care networks or teams involving secondary care specialist and specialist community health and social services staff in order to redesign care for people with complex needs with emphasis on assessment and management of long term care rather than episodic acute care. The Review sees these developments as very relevant, particularly to the needs of people with dementia or severe, enduring mental health problems.

1.11 With regard to resources, the Review sees it as critical that information systems are sufficiently sensitive to accurately track expenditure on all aspects of the service.

RECOMMENDATION

1. While services for older people with mental health issues may be located within either a mental health or older persons' programme of care, they should be provided as a discrete sub-speciality, with a ring-fenced budget and clear protocols for accessing other programmes of care.

Key Considerations

- information systems should be in place which are sufficiently sensitive to determine expenditure on service provision for this population;
- there should be a single, defined commissioning service.

Current Service Provision

1.12 In the consultation with service users, carers and service providers, it was evident that there are many examples of excellent services and best practice in Northern Ireland. However, it would appear that many of these have developed organically, without in many instances an overall strategy either within or between Boards and Trusts being in place. A number of the Boards and Trusts consulted were either beginning to develop, or had just developed, a Dementia and Mental Health Issues of Older People Strategy, as this Review was getting underway.

1.13 A number of deficiencies in current services identified by service users, carers and service providers highlighted the need for:

- a more collaborative and inclusive approach to care planning, i.e. involving service users where possible and carers at all stages of the planning process;
- a whole systems approach to designing services where the social, physical, emotional and spiritual needs of the individual are taken into account; and
- equity in accessibility to services.

Where We Want to Be

1.14 The Review considers that older people with mental health issues should be able to look forward to a response from services which:

- respects their individual autonomy and is person-centred;

- demonstrates fairness and justice – resources for services should be allocated and managed according to criteria which are transparent and which demonstrate equity;
- offers partnership with users and carers in the development, evaluation and monitoring of services;
- provides delivery of high quality, effective treatment, care and support;
- provides services which are readily accessible;
- delivers continuity of care and support for as long as is needed;
- provides a comprehensive and co-ordinated range of services and accommodation based on individual needs;
- provides comprehensive and equitable advocacy support, where required or requested;
- promotes independence, self-esteem and social interaction through choice of services and opportunities for meaningful employment;
- promotes safety of service users, carers, providers and members of the public;
- provides staff with the necessary education, training and support; and
- subjects services to quality control, informed by best practice evidence.

1.15 To achieve this, it will be essential that:

i. there are sufficiently trained staff to directly deliver care and support;
ii. different disciplines from health and social services backgrounds work in partnership both within and between the disciplines to provide a joined-up and coherent service to service users and carers;
iii. sufficient information is provided to service users and carers to empower them to be part of the multi-disciplinary team in influencing the care and support they receive; and
iv. an implementation and monitoring mechanism is established to help ensure that the proposals put forward in this Review are acted upon over the next 5, 10, 15 years and beyond.

CHAPTER 2

THE NATURE AND MAGNITUDE OF MENTAL HEALTH PROBLEMS IN LATER LIFE

2.1 The main mental health problems in later life include dementia, depression, delirium and other psychiatric disorders, including anxiety, psychoses and drug and alcohol problems. None of these are inevitable consequences of ageing, although the prevalence of dementia does increase with age.

2.2 The Review focused primarily on dementia and the functional mental illnesses which older people can experience, i.e. depression, anxiety and other psychiatric illnesses. Consideration of drug and alcohol related issues is covered in the Review's report, "Alcohol and Substance Misuse"; Alcohol Related Brain Damage, although referenced in chapter 8, is dealt with primarily within the Review's report, "A Strategic Framework for Adult Mental Health Services". Delirium is considered within the section on liaison psychiatry in chapter 7.

Dementia

2.3 Over the past 15-20 years, definitions of dementia have become much more precise in terms of the clinical features by which it should be identified. Deterioration in intellectual performance from a previous level must be accompanied by a significant decline in personal and social function and other causes for these impairments must also be excluded, e.g. general medical illness or toxicity (Cantley, 2001).

2.4 Dementia is a clinical syndrome characterised by a widespread loss of mental function, with some or all of the following features:

- memory loss;
- language impairment;
- disorientation;
- change in personality;
- self neglect; and
- behaviour which is out of character.

(NSF for Older People, 2001)

2.5 It has a number of causes, the most common of which is Alzheimer's Disease.

2.6 Different dementia sub-types can generally be identified by their mode of onset, the presence of particular neurological or psychiatric features and the course which the illness takes.

2.7 The Social Care Institute for Excellence, in their Practice Guide on Assessing the Mental Health Needs of Older People (January 2003), highlight the limitations of adopting a "disease only" perspective:

> "If we view dementia only as a 'disease', then we are tempted to abdicate our fundamental responsibility as human beings for the welfare of our fellows, and leave it to scientists in laboratories to discover the pill, potion, gene or magic bullet that will 'treat' or even cure dementia. But if we see dementia as a condition of which degenerative brain disorder is only one part, but which is fuelled by the fear, anxiety, shame and incomprehension of both the person concerned, those who they are in contact with and the wider society – then we can begin to see that we have a role to play for ourselves."

Functional Mental Illness (FMI)

2.8 The term "functional mental illness" is a generic term coined when it was believed that these disorders were not associated with a biological cause, although we now know that biological factors can play a part in many of these conditions. Although the term "functional mental illness" is still widely used, the Review is mindful that this term may become obsolete in the future.

2.9 In older people, the most prevalent functional illness is depression. Less common, but also present, are other psychiatric illnesses, such as delusional disorder (schizophrenia/paraphrenia), schizo-affective disorder and bipolar disorder (manic depressive disorder).

Terminology

2.10 The Review has adopted the term "mental health issues" as a summary term for use throughout this Report. This term includes anxiety disorders, mood disorders such as depression and mania, alcohol and drug misuse, psychotic mental disorders such as schizophrenia, acute confusion (delirium) and dementias.

Prevalence Rates

Dementia

2.11 Dementia is predominantly a disorder of the very elderly. At age 75, the prevalence rate is approximately 10 per cent. The prevalence doubles with every five years of increasing age, with approximately 40% of the total population over the age of 85 likely to be affected. There is some evidence to suggest however that beyond the age of 90, the risk of developing dementia begins to level off.

2.12 It is difficult to arrive at precise prevalence rates for dementia given the large number of people with the condition who are not in contact with health and social care providers. The Dementia Policy Scrutiny Report (1994) estimated that there were 12,448 people with dementia in Northern Ireland (Regional Information Branch, DHSSPS). A recent report to the Alzheimer's Society (2007) on the prevalence and economic cost of dementia in the UK (produced by King's College, London and London School of Economics) however estimates that there are 16,000 people with dementia in Northern Ireland and that this figure is projected to increase to 20,500 by 2017 and to over 47,000 by 2051. This represents a percentage increase of 30% and 200% respectively.

2.13 The Report estimates that of these 16,000 people, 396 have young-onset dementia (onset before the age of 65 years). However given that data is based on referrals to services, this number is likely to be an underestimate. The true figure may be up to three times higher.

2.14 Also of significance is the fact that, of the late-onset dementia group, there are approximately two women for every man affected.

2.15 As can be seen, the population of people with dementia is set to increase by 30% in the next ten years (by 2017). This will have a major impact for planners and commissioners involved in health and social care provision. It is imperative that services are planned now to meet increased need in to the future.

2.16 Of those people in the 65+ age group who have dementia, 30% will have mild dementia, 42% will have moderate dementia and 28% will have severe dementia. These figures are also significant for planners and commissioners in helping to determine likely demand for each type of service across the continuum of care.

Functional Mental Illness (FMI)

2.17 Mental illness in older age is very common across all care settings, however is often unrecognised due to the nature of the symptoms and the fact that many older people live alone. Depression in people aged 65 and over is especially under-diagnosed (Le Katona C. et al. 1991; Freeling P. et al 1985) and this is particularly true of residents in care homes (Mann A. et al. 1984). Rates of depressive illness in older people vary between 1 and 3%, but 10-15% of older people have depressive symptoms (Burns et al 2002; Simpson and de Silva, 2003). Unlike dementia and many other disorders, there is no obvious age-related increase in prevalence. People in their 90s have lower rates of depression than people in their 60s and 70s.

2.18 Conservative estimates of mental health problems in older adults suggest a prevalence of perhaps 40% of people attending their GP (Kendrick et al. 1991). Forty per cent of older people in residential care and up to 65% of those who are medical in-patients experience depressive symptoms (Burns et al 2002). The exclusion of these two groups of service users from most community surveys of mental ill-health has probably led to the relative under-estimation of depression in older people.

2.19 Prevalence rates for mental health problems in Northern Ireland are estimated to be 25% higher than in England (DHSSPS, 2003) linked to higher levels of social and economic deprivation, unemployment and the impact of the troubles. While there are no age-specific statistics available, older people have not been immune from the impact of these factors and indeed may have been particularly affected by them. One could therefore assume that this statistic is equally applicable to the over 65 year old population.

Interface of Depression and Dementia

2.20 Major and minor depression often occurs in patients with dementia and can be associated with deterioration in cognitive functioning. Although the majority of people with dementia do not develop major depression, more than half suffer from one or more depressive symptoms (Gruber-Baldini, 2003). There is an overlap between dementia and depressive symptoms and it is often difficult to determine whether the dementing illness or depression is the underlying pathology.

2.21 Depression in dementia brings additional disability to patients and their carers. Clinicians treating people with dementia, should routinely assess for depression and treat it, because successful treatment can improve many dementia-related outcomes (Boustani and Watson, 2004).

Ethnic Minority Groups

2.22 Prevalence rates of dementia and functional mental illness among ethnic minority groups are difficult to determine. Marshall (1998) as cited in Patel N. (1990) suggests that “the world of dementia is colour blind and minority communities are dementia blind”. Difficulties in arriving at precise figures are exacerbated by language barriers, reluctance to accept outside intervention, difficulties negotiating complex health and social care systems and the inappropriateness of diagnostic tools which were developed for use in white, indigenous populations.

2.23 The Chinese community is the largest single ethnic minority group represented in Northern Ireland, comprising 51% of the total ethnic population. There are estimated to be 8,000 Chinese people living in Northern Ireland, the majority of whom are located in the Greater Belfast area. There are also significant numbers in Craigavon, Lisburn, Newtownabbey and North Down. The Chinese community is growing at a faster rate than the general population (Irwin and Dunn) highlighting the need for this user group to be reflected in commissioning and service planning processes.

2.24 There are currently no statistics available in relation to prevalence rates for dementia or functional mental illness within ethnic minority populations, highlighting the need for primary local research in to this area. The difficulties in obtaining accurate statistics is acknowledged, given for example that less than half of Chinese people are registered with a GP (Chinese Welfare Association, 2006).

RECOMMENDATIONS

2. Health and Social Services Commissioners and Providers must have in place a detailed analysis of the demographic detail of their respective rapidly expanding older populations to effectively assess need and plan for current and future provision for those older people with mental health issues. This analysis should include identification of older people from ethnic minorities.

3. Health and Social Services Commissioners and Providers should undertake a scoping exercise of current service provision for older people with mental health issues, identifying shortfalls in provision, unmet need and the service provision anticipated for the next 10 years.

Legislative and Policy Context

Dementia Policy Scrutiny

2.25 While the community care policies developed in Northern Ireland in the 1990s (People First, DHSS, 1991) provide a policy framework that embraces dementia, this overarching policy had only limited impact on the development of coherent dementia services. The Dementia Policy Scrutiny, commissioned by that Department in 1994, provided an opportunity to establish a strategic direction for the development of dementia services and to provide guidance on best practice for purchasers and providers.

2.26 The Scrutiny Action Team's major recommendations were grounded on the need to establish dementia services on a sound and regular footing, with a clear administrative base, ensure the development of effective and well-targeted services, identify and meet need in a timely and appropriate manner and contribute positively to enabling people with dementia and their carers to live full and independent lives, ideally in a community setting. Recommendations (33 in all) were split into two groups: those which were to be implemented immediately, with limited resource consequence; and those which would be implemented progressively as part of a dementia strategy. The latter were recognised as possibly having more substantial resource consequences.

2.27 No formal audit of achievement in relation to meeting recommendations has been undertaken by the Department since the launch of the Scrutiny Report in 1994. Progress in meeting recommendations has been variable throughout Northern Ireland and many of the issues identified still remain and as such have formed part of the considerations of this current Review. The Policy Scrutiny Report also confined its terms of reference to dementia: the needs of older people with functional mental illness were not considered.

2.28 A summary of key legislation and policy underpinning work with older people with mental health issues and their carers is included in Annex 2.

2.29 The Bamford Review has also given detailed consideration to the need for new legislation for Northern Ireland, the overall purpose of such legislation, the guiding principles which should underpin it, and the need for a comprehensive approach to respecting and protecting the dignity of people with mental health problems or a learning disability. The report on its proposals for reform will be published in the near future.

2.30 Capacity legislation, which has been introduced in Scotland and in England and Wales, is the main source of guidance in relation to dealing with consent, property and lifestyle issues. This legislation is predicated upon an assumption of capacity, unless it can be proven otherwise, and incorporates the values, principles and philosophy which underpin it. Staff will need to adopt more of a value-based approach to their work in this area, starting with the presumption that people can make decisions.

2.31 To help ensure that vulnerable people can make their voices heard, the legislation introduces independent mental capacity advocates. There is currently very limited access to advocacy services available to older people with diminished capacity in Northern Ireland.

2.32 Legal issues formed part of the public consultation exercise which was undertaken as part of the this dementia and mental health issues of older people Review. The key issue highlighted was the considerable lack of accurate information among staff and carers.

Human Rights Issues

2.33 The Review has identified a range of areas in the context of work with older people with mental health issues which may give rise to human rights concerns. Key areas of risk in current practice include:

i. People with dementia being cared for in locked wards/care homes.
This practice could contravene Article 5 (The Right to liberty) and Article 8 (Right to family life). The recommendations of the Review promote long-term care options for people with dementia to be extended to include options such as specialist home care, supported housing options, assistive technology, dementia design specific care homes, all of which can manage risk in more sensitive, person-centred ways. It is essential that commissioners and providers continue to develop these care options.

ii. Consent to admission to care homes.
Admission without informed consent could contravene Article 5 (Right to liberty) and Article 6 (Right to a fair hearing). This issue should be addressed through capacity legislation, in particular, the assessment of capacity and use of advocates.

iii. Financial ceilings imposed on the provision of home care.
Boards and Trusts will need to be able to clearly demonstrate policies on fair access to care, with clear criteria for homecare, including equality screening.

iv. Delayed discharges/waiting lists/lack of preventive services.
This could give rise to challenge in relation to Article 8 (Right to family life) as lack of resources can cause health to deteriorate, thereby adversely affecting family life. This is primarily a resource issue and it is unclear what the legal position in relation

to human rights would be. The Review clearly endorses the view that older people with mental health issues should have access to the same range of services, including intermediate care, as the rest of the population and that services should not be denied on the basis of age.

v. Use of Restraint.
This could contravene Article 3 (Prohibition of torture), Article 5 (The Right to liberty) and Article 14 (Prohibition of discrimination). Trusts will need to ensure that policies on the use of restraint are value-based and comprehensive in order to address all of the manifestations of restraint. These policies need to be supported by the required procedures, training and education, as well as regular audit feedback loops. This issue is further explored in chapter 6.

vi. Lack of Advocacy Services.
This could also contravene Article 14 (Prohibition of discrimination). The provision of advocacy services has been recommended by the Royal College of Psychiatrists (2005). It is possible that new capacity legislation will require the availability of advocacy. This issue is further addressed in chapter 3.

vii. Elder Abuse.
Article 3 (Prohibition of torture) is the key consideration here. All Trusts, including hospitals, will need to ensure that the regional policy concerning the protection of vulnerable adults is fully and effectively implemented.

Funding of Long-Term Care

2.34 The Review's public consultation exercise supported the view of the Royal Commission that personal care should be provided free of charge.

2.35 A key issue of concern for carers related to top-up fees. The position adopted by the Review is that top-up fees should not be applied in relation to provision of basic minimum standards of care. The DHSS Circular HPSS R (3) 1/93 prohibits Trusts from "requiring a contribution from a third party in cases where the Trust itself decides to offer someone a place in a more expensive home than it would normally use, for example, where there is at the time no substitute available accommodation at the cost the Board would usually pay for accommodation".

Realistic tariffs for residential and nursing care which reflect the additional care and supervision needs as well as the social/diversionary needs of older people with mental health issues should be agreed. This process would be facilitated by the development (by the Regulation and Quality Improvement Authority) of a set of specifications which reflected the particular needs of this service user group.

RECOMMENDATION

4. Realistic tariffs for residential and nursing care, which reflect the particular needs of older people with mental health issues, should be agreed.

Review of Public Administration

2.36 The Review is mindful that the decisions on the Review of Public Administration announced by the Under Secretary of State in November 2005 will have major implications for the way health and social services are delivered within Northern Ireland. The Review considers it essential, however, that the commitment offered by the Minister to the development of new ways of managing performance which are patient-led, patient-centred and patient-responsive is realised. This will only be achieved through robust and comprehensive consultation with users, carers and service providers.

CHAPTER 3

INFORMATION AND ADVOCACY

Introduction

3.1 Too often people with mental health issues and their carers have difficulty accessing the information they want and even when they do, there can be problems understanding it, due to jargon, unclear language and hard-to-follow instructions. It is widely acknowledged that for older people with mental health issues and their carers, information regarding their condition is limited and not easily accessible (User Workshop, Age Concern Northern Ireland (2000). Without sufficient and timely information, it becomes more difficult for people to cope.

3.2 There are many sources of good general information available, however difficulty accessing this has been a dominant issue raised in consultations and discussions with all stakeholders involved.

3.3 A public information/awareness strategy is of highest priority and should help older people with mental health issues and their carers to understand their condition and become fully involved in decisions about their care and well-being.

3.4 The strategy should also provide information on the care options and all aspects of care available, particularly if these would have a significant effect on their daily life.

3.5 In order to meet individual needs and to provide the necessary support, the extent of information required needs to include definitions of the condition and illness, various treatments and interventions available and the possible impact of these on the individual's life. It is also essential that the individual is aware of all the current services that can be provided, including details on how and when to access these. The choice of services should include the full range of flexible support services, respite care etc, including information about advocacy, competency, legal issues and complaints procedures.

3.6 Resources need to be in place to enable people to have ready access to services, as and when required, in order to support both the individual and his or her carer. The information (including access to a 24 hour help-line and web-based provision) should be freely available and accessible in a range of public places, with programmes designed to educate society (including service providers) about care of older people with mental health issues.

3.7 There also needs to be a co-ordinated approach in relation to the access and provision of information and training. Joint working is important among all stakeholders, as without this, resources are wasted through repetition and duplication of services.

3.8 Information points should be available in a variety of locations, including Health and Social Services buildings. It may be advantageous to have, for example, the GP surgery as the main information point.

3.9 Public awareness information, including details on "prevention" and "early signs" should be in the general public domain to highlight the importance of a healthy lifestyle. People should be encouraged to see their GP at an early stage if there are any concerns regarding memory or mental health difficulties as research indicates the benefits of early interventions (Pratt and Wilkinson, 2001).

Best Practice Example

Directory of Care Organisations, Local Services and the Service you can Expect – Easy to read and understand Charter for People with care needs in Cornwall, 2004.

The special version of this booklet has been produced using graphics and language that are easy to understand and which may appeal to, engage with and inform a wide range of people.

People with Dementia Speaking Out

"I wanted to find out as much as I could about dementia, but all the books I read were for carers and made me think what a burden I was going to be" (Spicker and Gordon 1997).

3.10 After diagnosis, or even before, some people with dementia will often search out information about what is happening to them in order to gain a better understanding. There is, however, often little information available.

3.11 Information for people with dementia should be provided in a clear, easy-to-read format and address possible areas of concern, information about available treatments, the prognosis, how to deal with problem situations, the type of help available and where this can be accessed. Other sections should include information on legal and financial matters. It is essential that information is available, free of charge and provided in a variety of forms that are acceptable and easy for the target audience to understand. Internet options should also be explored.

Best Practice Example

"Facing Dementia" booklet published by Alzheimer Scotland. This booklet is for people who have a diagnosis of dementia and helps to give an understanding of the condition. It is written by people with dementia.

Carers Speak Out

"People in general don't understand dementia and it gets so much negative publicity. I felt lost when my husband was first diagnosed and had so many unanswered questions. It took a long time before I got information and found out who I could contact for help when it was hard to cope at home. People need information as soon as they get the diagnosis so they know what they are dealing with." (a carer)

3.12 All carers have a need for information and advice on the condition and prognosis, the practical implications, how and where to access services to support them, benefit entitlements and legal aspects (Gilliard and Rabins, 1999).

3.13 Information on the condition and available services are one of the supports which carers value most, alongside acknowledgement of their role and attention to their distress (New Zealand Guidelines Group, 1997; Nolan and Keady, 2001).

3.14 Some carers will want to know everything about dementia as soon as possible, while others will want a more gradual and staged exposure to information (Keady and Nolan, 1995). Both positions are equally valid and it is important that the professional should be led by the carer in determining the nature and level of information provided. Carers may also need to hear the same information repeatedly (Cantley, 2001).

Best Practice Examples

"ACROSS" – An information booklet for carers produced by Newry and Mourne Trust in partnership with the Alzheimer's Society

"Dementia Handbook" – An information booklet for people with dementia, their carers and professional staff produced by Down Lisburn Trust.

General Public Awareness

3.15 Information about mental health issues in older age needs to be widely dispersed in many formats so that general knowledge regarding early signs of these conditions are well recognised by the public. While there has been increased media exposure of mental health issues for older people, particularly in relation to dementia, there is still a long way to go before there is wider acceptance and social inclusion. It is imperative that the health promotion needs of older people with mental health issues are given the same priority as other service user groups. It must also be recognised that a health promotion strategy must encompass physical as well as mental health perspectives.

Best Practice Example

Alzheimer Scotland has produced a guide and leaflet, "Dementia-friendly communities", to encourage everyone in the community to be more aware of people with dementia and the ways in which they can be helped.

Training and Education

3.16 Training and education programmes are required for all staff working in public places so that they have the necessary knowledge and skills to respond to queries regarding services and to direct people to where they can obtain information and advice.

3.17 Investment in further education and training for people working in this field of work is needed as the lack of experienced staff to meet current service demands has been noted by both carers and service providers as part of the consultation process. This also needs to include training for staff working in the independent sector.

3.18 Carers and older people with mental health issues have an important role to play in shaping the training that is provided (Killeen, 2001).

3.19 There is also considerable evidence of the benefits of education and training programmes for carers. It has been found to improve adjusted rates of survival at home, with fewer deaths and to delay institutionalisation (Brodaty et al. 1997).

Best Practice Examples

"Depression and Dementia in Older People" – an interactive training CD Rom specifically aimed at doctors and other health care professionals (produced by Kiss of Life Multimedia Ltd.).

"Coping with Maggie – Caring for Margaret". This is a training and information resource pack for carers of people with dementia produced by Homefirst Trust.

"A Clear Path" DVD and training manual – an information resource for Carers and training pack for all staff groups.

RECOMMENDATIONS

5. A Policy and Practice Development Centre for Mental Health Services for Older People should be established which would provide information, training, consultation and research and help secure comprehensive and relevant dementia service provision.

6. Public education programmes, focusing on promotion of good mental health and prevention, should be developed.

7. The DHSSPS should ensure from a strategic point of view, that health promotion in relation to mental health issues is given the same priority as for other service user groups.

8. Dementia and mental health issues in older age should be included in all training programmes for health and social care staff (including those working in the independent sector). This should be undertaken on an inter-agency and multi-disciplinary basis where possible. Training and education programmes for carers should also be provided.

[Unsuccessful attempts were made to achieve a viable Dementia Services Development Centre in Northern Ireland between 1992-1999. An inter-professional, inter-agency group established Dementia Development N.I. in 1995 as an incorporated company limited by guarantee. It was dissolved in 1999 after persistent efforts failed to secure sufficient sustainable support. Although the need for such a centre was recommended in the Policy Scrutiny Report of 1994, Northern Ireland remains the only part of the United Kingdom without a Dementia Centre.]

Key Considerations

Local information directories for all areas, detailing the services and facilities available for people with dementia, should be developed. On-line directories have the advantage of being easily updated to ensure the currency of information.

- An information package (specific to Northern Ireland), including a booklet on dementia, should be made available to people with dementia and their carers at the time of diagnosis, with access to additional information as required/requested.

- All information should be made available in a range of formats (e.g. posters, leaflets, internet, CD) and languages to meet the needs of people with disabilities, different ethnic backgrounds. The information should be written in a user friendly, non-jargon format, with the use of symbols and pictures in addition to text to assist people with dementia and functional mental illness to understand their diagnosis and how and where they can obtain support.

- Individuals and their carers should have access to a contact point or 24 hour helpline to ensure that advice and support is readily accessible, thereby minimising the risk of a crisis developing.

The Provision of Advocacy for People with Dementia

3.20 Dementia advocacy seeks to support people in communicating their views and wishes and to enable people to access their rights. Dementia advocacy also seeks to enable people with dementia to make informed choice about, and to remain in control of their own care.

3.21 Many people with dementia face serious disadvantage and are vulnerable to various forms of discrimination and abuse. For many, the experience of the illness is characterised by reduction and exclusion – often unintentional but nonetheless damaging to individuals whose worlds have already been eroded. People are denied a part in decision-making about most aspects of their lives and frequently denied the knowledge of their own condition. Perceived difficulties of communication are used to justify non-engagement with a person with dementia; and issues around risk may lead to further disempowerment.

3.22 Independent advocacy for people with dementia aims to redress some of the effects of such disadvantage through supporting people with dementia, for example, to:

  - play as full a part as possible in decisions about everyday matters affecting their lives;
  - play as full a part as possible in major life decisions, e.g. about moving home;
  - obtain outcomes which they want;
  - prevent outcomes which they do not want;
  - ensure that their needs are met;
  - protect their rights and secure their entitlements;
  - promote their well-being; and
  - improve their quality of life.

3.23 A specialist dementia advocacy service should offer specific expertise and understanding of communication with people with dementia, of the variable progression of dementia illnesses and of best practice in dementia care. Expertise should also include substantial knowledge around welfare and legal rights and can also be used where dementia may be an additional barrier to expression of individual need, for example, with people with alcohol-related dementia or those with other mental health problems.

3.24 Advocates must work within a declared code of conduct to ensure that the person's wishes may be expressed despite the complexity brought about by multiple health concerns.

3.25 Dementia advocacy will involve some or all of the following processes:

- building a relationship with the person with dementia;
- ascertaining the person's views and wishes;
- enabling people to exercise choice;
- supporting people in having their views heard;
- representing people's interests;
- influencing (often powerful) others; and
- resolving conflicts.

3.26 Dementia advocacy must be underpinned by these values and principles:

- autonomy;
- empowerment;
- consent;
- acceptance and respect;
- choice;
- citizenship;
- inclusion;
- confidentiality;
- loyalty to the person with dementia; and
- independence from other interests.

Advocacy for Older People with Functional Mental Illness

3.27 Many of the principles outlined above apply equally to the provision of advocacy support to people with functional mental illness, who are often similarly excluded from decision-making processes affecting their own lives, particularly where there are perceived to be high levels of risk.

3.28 Carers' views are important in their own right, but may be different from those of the older person with the mental health issue.

3.29 The role of advocates in supporting and assisting people to represent their views should be welcomed.

RECOMMENDATION

9. Independent, specialist advocacy services should be available for older people with mental health issues. These should be commissioned on a regional basis to ensure equity of access and service delivery to agreed standards.

CHAPTER 4

PERSPECTIVES FROM SERVICE USERS AND CARERS

Introduction

4.1 At the heart of any review of mental health services for older people is the person with dementia or mental illness and his or her carers. As part of the Review, a series of consultation meetings were held to capture the views and experiences of users and carers so that this information could be used to influence and shape this Report and its recommendations.

Service Users

4.2 For the individual, the onset of dementia or a serious mental illness can be devastating. The things they were once able to do independently, or remember, they are no longer able to, resulting in frustration and confusion. Understandably, this can lead to anger and "challenging" behaviours, as they try to make sense of what is happening. Often no one tells them their diagnosis to help them understand. As their condition deteriorates and "strangers" increasingly do things for and to them, they lose more and more of their dignity and self-worth.

4.3 It is vital to remember that the individual with dementia or mental illness is a person with a full life story who has been a valued member of his or her family and society for possibly 60 or 70 years. Dementia or mental illness does not take this away. They are still a person of worth and value and should be treated as such, with dignity and respect. They should be given the right to be involved in planning their own care and enabled to make decisions as far as possible. They should be treated as an individual, with support tailored as far as is possible, to take account of their needs, likes and dislikes.

Carers

4.4 Family carers provide the vast majority of care and support to older people with mental health issues. Community care policies largely depend on the continuing contribution of carers who significantly reduce the amount of input that social services and other agencies need to make.

4.5 The Valuing Carers Strategy (DHSSPS, 2002) highlights that "it is in society's interest to sustain this motivation to care and to see that appropriate packages of support are assembled for people who are willing and able to care for others…. without jeopardising their own health or financial security or reducing their expectations of a reasonable quality of life". It is also important, however, to recognise when it is inappropriate to expect a carer to continue and when strategies should be aimed at helping them to relinquish this role (Nolan et al. 1996).

4.6 Carers' central role must be fully acknowledged by commissioners, planners and service providers in how they modernise services to provide ongoing and meaningful support to carers. A systematic, planned approach that engages the carer as an integral part of the system of care has benefits for users, carers and services (Oyebode, 2005).

4.7 The Forgetful but not Forgotten Report (RCPsych, 2005) states that there should be special sensitivity to the effects that caring for a person with dementia may have on a caregiver. Caring for people with dementia in particular is associated with higher levels of depression and stress (Livingston et al. 1996). Relationship changes which occur in the caring relationship can be very emotionally distressing and can involve both practical and health implications for the carer.

4.8 Carers often report that they feel isolated and have to cope alone. During the consultation exercise, carers stated that they found it "difficult to access support outside of the home due to their caring responsibilities". The example was given by one carer of 'feeling like a prisoner in their own home'. Carers spoke of "feeling abandoned" and "being left to get on with things if they seemed able to". Others spoke of having to sell property or re-mortgage their home just to keep going. A number of carers stated that they had had to give up their jobs to continue with their caring responsibilities.

4.9 Carers' distress did not cease when their relative was admitted to a care home. Rather, this decision led to another set of concerns, including feelings of guilt and despair, feeling excluded from care planning and concern over the quality of care provided.

4.10 The content of the remainder of this chapter is taken directly from the consultation report and provides a summary of the key concerns of users and carers. Recommendations in relation to addressing these issues are integrated throughout the Report.

First Contact and Appropriate Pathways for Specialist Support

4.11 The GP is often the first point of contact for both user and carer, offering an important opportunity to provide information, support and treatment, which can make a real difference to the lives of users and carers. GP training is required to facilitate earlier identification of dementia, appropriate referral pathways and signposting of support for both users and carers.

4.12 Carers report feeling excluded by the primary care team and left to cope alone after a diagnosis has been made.

Prevention

4.13 The link between unhealthy lifestyles and dementia should be explicitly promoted.

Information

4.14 Users, carers and families need more help to :

- understand the diagnosis;

- know about the range of support services and treatments available;
- understand the legal issues involved and receive appropriate guidance and advice;
- access information from one source on an ongoing basis. The information should be locality specific; and
- look after their own needs.

4.15 There is a need for increased public awareness about dementia.

Advocacy

4.16 There is a need for advocacy services and support for vulnerable individuals.

Making Complaints

4.17 Carers need better information and support to complain when dissatisfied with services.

4.18 The Regulation and Quality Improvement Authority needs to exercise more rigorous monitoring and regulation of the care provided in independent homes.

Equity of Access

4.19 Ageist attitudes within the system need to be challenged.

4.20 Access to services for those over 65 are inequitable compared to younger people.

4.21 A wider range of treatments, therapies and activities need to be available including Cognitive Behavioural Therapy, Physiotherapy and appropriate activities in all care settings.

4.22 There should be increased access to day care.

4.23 Provision for younger people with dementia is limited and needs to be considered in a more strategic way.

4.24 There is recognition that mental health services for older people fall between service areas.

4.25 Accessing relevant services is more difficult for people in rural areas.

4.26 Users and carers in all settings, expect staff to be appropriately trained, patient and competent and services to be much better co-ordinated than they are at present.

Person-centred Services

4.27 The culture of care in all care settings should have user needs at the centre and clear leadership in place to promote this.

4.28 Approaches to care planning need to be much more person-centred and carers need to be included in the care of their relative. Carers and families need to be supported to be involved as they wish, in the care of their family member, whether they are in hospital, residential or nursing home settings. Good communication is the key to this.

Integrated Services

4.29 There is a need for more effective liaison between general hospitals and psychiatric services.

4.30 Communication between the relevant professionals across all settings needs to be promoted and supported to ensure appropriate information sharing.

4.31 Dementia services should be specialist and should sit where service users most benefit and are likely to attract resources.

4.32 The needs of older people with a learning disability and dementia require joined up approaches between the relevant specialisms to ensure their needs are recognised and met.

Medication

4.33 Review of medications needs to be more regular and thorough with relevant professionals clear about their respective responsibilities.

4.34 Improved medicines management is needed, from better co-ordination between existing medication regimes and new medications prescribed in hospital to helping carers cope with the proper administration and review of medication at home.

4.35 There are concerns about over sedation in some circumstances.

Carers and Employment

4.36 Carers, who choose to return to work following a caring role, need support to do so.

Respite Care

4.37 Access to good quality respite services needs to be improved. Carers need the reassurance of knowing that they have easy access to emergency respite options should they become ill themselves.

Long-Term Care and Support

4.38 Service users should not be kept in hospital for long periods of time. They should be enabled to stay at home if at all possible, facilitated by intensive support mechanisms.

4.39 Housing options should be further developed, including use of assistive technologies. It is essential that these services are actively integrated in to local communities.

4.40 There are currently insufficient places available in specialist dementia units.

4.41 Physical care environments need to be in keeping with the needs of people with dementia.

4.42 Ongoing staff training is needed for non-specialist staff working with people with dementia. This should be supported by specialist staff/teams.

4.43 Long-term care settings are increasingly recruiting staff from overseas. Communication issues inevitably arise. This needs to be recognised and addressed through ongoing training and education programmes.

4.44 Continuity of care is important to users and carers and service providers should make this a priority through appropriate recruitment and retention practices. Building caring relationships with service users should be encouraged and supported.

In-patient Care

4.45 More attention should be paid to the needs of older people with dementia or mental illness in acute medical settings.

4.46 Carers are concerned about the quality of basic care available and the increasing expectations that families should provide that care.

Ongoing Engagement with Users and Carers

4.47 Users and carers expect that following the Review, they will be afforded ongoing opportunities and mechanisms to assess progress and provide feedback.

CHAPTER 5

THE CONTINUUM OF CARE

Introduction

5.1 The Review is committed to ensuring that the continuum of care available for older people with mental health issues is:

- person-centred;
- empowering;
- reflective of the range of presenting needs and care preferences;
- holistic;
- flexible in response;
- responsive to changing needs;
- locally delivered, as far as possible;
- as seamless as possible, offering continuity of care;
- focused on achieving positive outcomes in terms of health and quality of life; and
- effectively monitored.

5.2 The needs of older people with mental health issues change throughout the span of their illness. Services and supports which are required at the stage of initial diagnosis are likely to be very different from those required in the latter stages of illness. The diagram in Annex 4 seeks to depict this journey.

5.3 Services also need to be individually tailored to meet identified needs and reflect the care preferences and aspirations of service users and carers.

5.4 Highly individualised, needs-led responses require a complex array of services across a range of tiers. To ensure that the care pathway for service users and their carers is as seamless, coherent and integrated as possible, it is essential that these services are underpinned by careful planning, good management practices, flexible budgets, robust communication systems, effective multi-disciplinary and multi-agency working and meaningful engagement with service users and carers.

5.5 The Review has endeavoured to develop a model of care for older people with mental health issues which considers the likely supports and services which will be required, from independence and low level practical home-based support through to specialist care, and the relationships which need to exist between community and primary care, specialist services and hospital based provision.

5.6 The Review supports the view that older people with mental health issues should be looked after in the context of their own home for as long as possible, unless there are very good reasons why this cannot be the case.

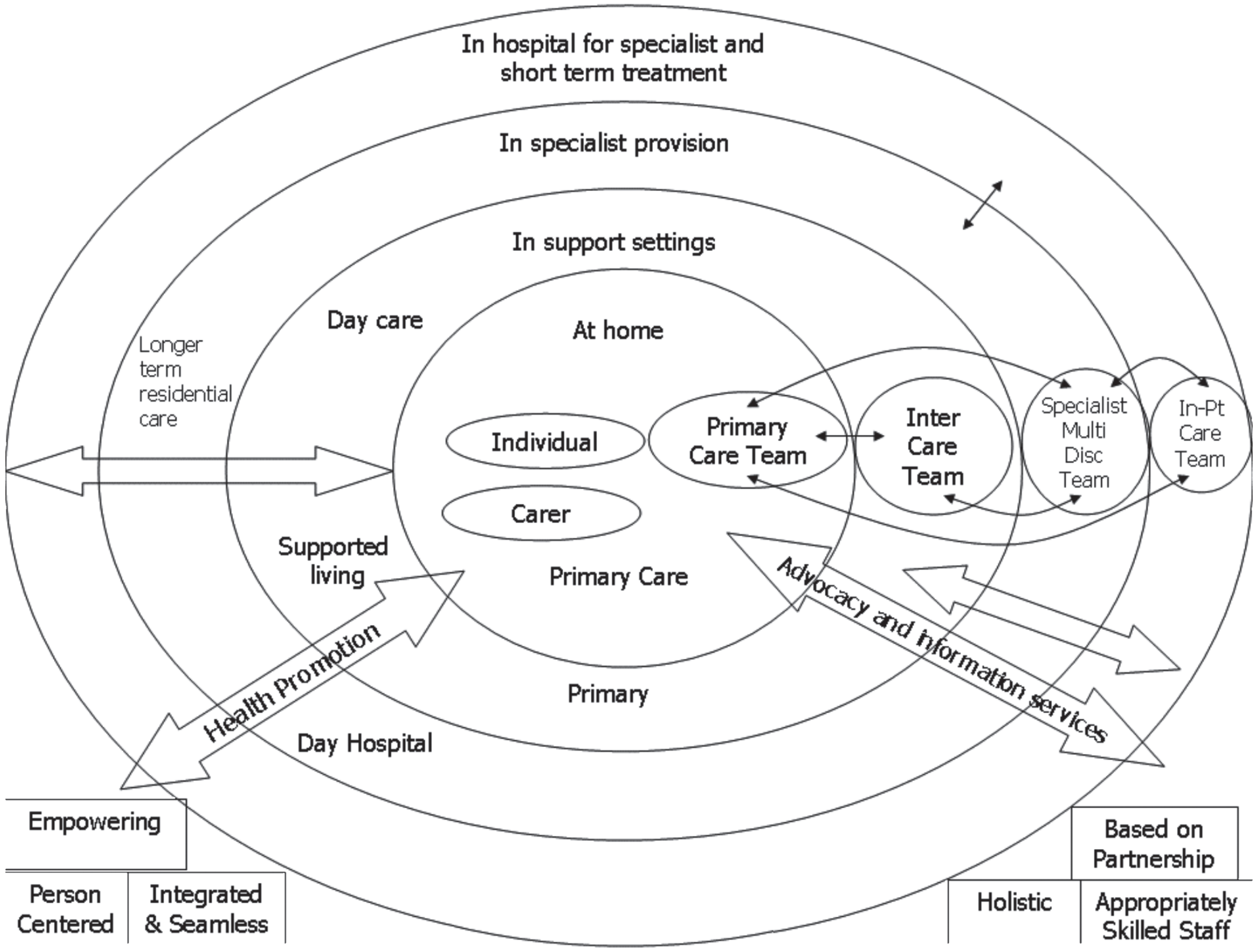
5.7 The Review also acknowledges that in this context, much of the support offered to the older person will be provided by family, community and voluntary sector services.

5.8 The next two chapters consider the framework of services across the care continuum, identifying key issues, underpinning principles and recommendations.

5.9 The diagram on page (?) represents the continuum of care for the older person with mental health issues and his or her carer across this continuum of care. It highlights that people can move both ways across the care continuum dependent on their needs at any given point in time. Advocacy and information support and health promotion should underpin all service responses.

5.10 Services, irrespective of level, should be person-centred, holistic, integrated and seamless, based on partnership, empowering and delivered by appropriately skilled staff.

The Care Continuum



CHAPTER 6

CONTINUUM OF CARE - PRIMARY AND COMMUNITY CARE SERVICES

6.1 For the majority of older people with mental health issues, it will be the primary care team who will provide most of the care required. Primary care is the cornerstone of health and social care provision and most people look to primary care for help, in a local setting, near to where they live. It acts as a first point of contact and as a gateway to a wide variety of services, both within the primary care system itself and to other parts of the wider health and social services system. It is important to recognise, however, that community care comprises both primary and specialist provision.

The "Everybody's Business" Report (DoH, 2005) sees the key tasks of primary care as comprising four elements:

- health promotion and helping people to care for themselves and their condition more effectively;
- recognition of mental health problems;
- formulation of a care plan, including support for family carers; and
- referral to specialist services for the those who have complex needs or who pose high levels of risk.

Primary Prevention of Dementia and Mental Health Problems in Older People

Dementia

6.2 In recent years there has been increased interest in understanding the factors that cause dementia, or increase the risk of it developing and in investigating how these factors could be modified. The prevalence of dementia could be reduced by as much as 50% if risk reduction strategies were successful in delaying the onset by five years. There have been several recent reviews of the subject (NHS Health Scotland, October 2003; Purandere et al. 2005).

6.3 The research on risk factors for dementia is complex and much remains to be clarified. Evidence suggests that there is no single cause for dementia and hence no single solution, but there are some suggestions of possible scope for intervention. The clearest evidence is of an association between the so-called vascular risk factors (i.e. risk factors for stroke and heart disease) and dementia. Stroke itself increases the risk of dementia by 5 to 10 times. Hypertension and high cholesterol (especially in the form of increased low-density lipo-protein) in middle life, diabetes and smoking have all been associated with dementia and it seems reasonable that improvement of these is likely to reduce risk of vascular dementia. Recent work has suggested that these factors are also independently associated with Alzheimer's Disease. Obesity has also recently been linked with dementia.

6.4 The evidence for other factors is less clear, but there is some evidence suggesting stress management, physical and psychosocial activity may be helpful (Wang et al. 2002;

Mahandra and Arkin, 2003). Other work has looked at various components of the diet and, while there is not enough evidence to recommend specific supplements, it seems likely that a healthy diet with adequate levels of Vitamin B12, folic acid and Vitamins C and E may be useful.

Depression

6.5 Depression is the most common functional mental illness in older people and studies have shown it is often under-diagnosed and under-treated (DoH, 2005). Depression is the major cause of suicide in older people; it adversely affects quality of life and disability from physical disorder and is associated with an increased mortality.

6.6 About 13.5% of older people living in the community will have clinically significant symptoms of depression and, overall, about 2% will have a major depressive illness (Beekman et al. 1999).

6.7 There is little definitive evidence for prevention of depression in older people. However, depression in this group is known to be associated with social isolation and poor physical health. It seems likely that measures to promote social integration and a healthy lifestyle are likely to prevent some depression.

6.8 Depression is particularly associated with vascular disease (Baldwin and O'Brien, 2002) and improvement of vascular risk factors as mentioned above may reduce depression as well as dementia.

6.9 High levels of depressive symptoms are found in carers, especially those caring for someone with dementia (Alzheimer's Society, 1993; Livingston et al. 1996). A major contributor to stress is behavioural disturbance (Huckle, 1994). It has also been shown that psychosocial interventions can reduce the level of depressive symptoms in caregivers (Brodaty et al. 2003) and so seems likely that they may also prevent depressive symptoms in caregivers.

Early Detection/Case Finding

"The GP said I was getting old - what do I expect at my age. He wouldn't listen to me or my wife. I knew I wasn't well and when I got treatment I really felt better".

man with dementia following GP refusal to test for dementia

6.10 There is general agreement on the need for early detection of mental health issues in older people (NSF for Older People 7.7; Mental Health Services for Older People, Regional Report, DHSSPS 2003; User and Carer Consultation Report, 2004).

6.11 With dementia, early detection allows the person the opportunity to discuss their symptoms and treatment options, make informed choices about their future and, possibly by lifestyle choices related to cardiovascular risk factors, modify the course of their illness.

6.12 In functional mental illness, it will reduce distress to sufferers and their carers by earlier access to information, support and treatment and potentially reduce serious consequences such as self-neglect, self-harm or suicide.

6.13 Early detection will begin in primary care. GPs and other members of the primary care team require training in recognising the early signs of mental health issues in older people and must know who to refer to for further advice and assessment.

6.14 GPs are often the first point of contact for older people with mental health issues or for concerned carers or family members. It is clear, however, that many GPs have not received an update in dementia care since their undergraduate training. There is also often concern that GPs fail to detect mental illness, particularly depression in older people

The Forget-me-not Report (Audit Commission, 2002) found that less than half of the GPs surveyed felt they had sufficient training in dementia. Unless doctors are aware of the early signs of dementia, they are unlikely to consider the diagnosis (Rait and Walters,1999).

6.15 There is often uncertainty as to what is the best screening/assessment tool to use and debate as to whether a GP has time during a normal 10 minute surgery consultation to use it effectively.

6.16 Many of the carers who participated in the public consultation exercise, highlighted difficulties in making contact with the GP surgery, obtaining suitable appointment times and in getting repeat prescriptions. One of the suggestions made was for the establishment of a mechanism to fast-track help for carers, such as the caller being identified as a carer on the computer screen in the surgery.

RECOMMENDATIONS

10. Health and social care professional education and training at undergraduate and postgraduate level should include more training in the area of dementia and functional mental illness. This education should include experience of dealing with these conditions in the community.

11. Primary care staff should receive more training in the early detection of dementia and functional mental illness and recognise the benefits of doing this. The use of standard assessment tests should be encouraged.

12. Systems which are sensitive to the particular needs of carers should be in place within GP surgeries, e.g. flexible access.

Key Consideration

- There should be training and education programmes in place for all care providers, including domiciliary care staff, care assistants and community nurses to encourage earlier referral within primary care.

Arrangements for the Delivery of Primary Care

6.17 The first General Medical Services (GMS) contract for GPs, introduced in April 2004, strongly influenced the disease areas on which doctors in primary care focused and it made no specific reference to dementia or functional mental illness in older people. The new contract, starting in April 2006, has points allocated for the quality of care of patients with dementia and depression. The fine detail of this remains unclear and it is uncertain how GPs will tackle the new targets relating to these disease areas. It will take at least until April 2007 to get feedback on whether quality of care has improved.

6.18 It is also clear that effective communication with mental health professionals improves patient care. The option of having a lead GP within a practice, with a special interest in dementia, may help this process. A concise care pathway will allow the team to work efficiently and in a co-ordinated manner.

6.19 In some areas, the development of a locally enhanced service (LES) for the management of patients with dementia and functional mental illness may improve care further. This will require careful planning, with input from primary and specialist services to ensure they complement each other.

6.20 Where mental health issues are detected, protocols should be in place for the care and management of the person, agreed with specialist services. These should address issues of initial assessment, initial management and guidance for referral to specialist services.

6.21 Primary care should remain responsible for interventions for physical co-morbidities, sensory deficits and other disabilities.

6.22 All primary care staff should be able to offer a degree of support to people with dementia and functional mental illness. A tiered approach should be adopted, with simple, less intensive treatments available in primary care. This should include access to psychological therapies for older people. These should be delivered by practitioners with suitable training, experience and supervision. Link workers liaising between primary and secondary care may be appropriately placed to provide some of these skills. Local protocols should specify when more specialist interventions are necessary.

6.23 The voluntary sector makes a critical contribution to primary care of older people with mental health issues. Close links should be established and voluntary agencies should be encouraged to work together to provide local service/resource directories or to develop web-sites, which can be constantly updated.

RECOMMENDATIONS

13. Clear, local protocols should be drawn up jointly between primary care and specialist services.

14. Dementia care and care of older people with functional mental illness in the community should be considered as a Locally Enhanced Service (LES) within the GMS contract.

Generic/Specialist Interface

6.24 All people with symptoms suggestive of dementia should have an assessment from a health professional competent to make an accurate diagnosis, and to prescribe drug therapy, if appropriate. This is likely to be a doctor with training in dementia, but could include a specialist nurse (if part of a specialist multi-disciplinary team with medical input).

6.25 The consultation exercise has highlighted that users and carers are confused about how the service is organised and believe that communication needs to be improved and links between primary and secondary care strengthened.

6.26 Many patients with longstanding functional mental illness or new onset symptoms in later life will be managed in primary care but should have services readily available to them from secondary care.

Best Practice Example

North and West Belfast Projects in Ballyowen and Bruce House Assessment Centres, with nurse-led pre-assessment screening.

Domiciliary Care

"Our care worker is like a ray of sunshine - cheers up the day and lets me out for a while"

carer of man in receipt of domiciliary care

6.27 Most older people with mental health issues wish to continue to live in the community, where possible, with the support of informal carers. However, of those with dementia, 89% need some help with personal care, including continence, at least once a day. 62% need help with personal care at night (Assessment of Needs of Older People with Dementia, Scottish Report, 2002).

6.28 Consequently, there is considerable dependence on domiciliary support. For it to be effective, however, it must be flexible, responsive and delivered by trained staff.

6.29 Domiciliary care is support provided to individuals in their own home. It includes assistance with personal care, getting up/going to bed, feeding, medication, toileting and essential household tasks. For people with mental health issues, it can also include practical management e.g. assisting and prompting, ensuring bills are paid, medication is complied with or prevention of isolation.

6.30 The Dementia Policy Scrutiny (1994) stated that:

> “Purchasers should explicitly require dementia services to be delivered by adequately trained and skilled staff; and all service sectors should develop training strategies in respect of specialist dementia teams and all staff working directly with elderly people.”

6.31 Whilst greater emphasis is now placed on training, this is an area that requires considerably greater investment and development. The introduction of Domiciliary Care Standards by DHSSPS and the planned Registration and Regulation of the workforce is welcomed. This must, however, be adequately resourced. A balance needs to be established between ensuring good levels of service provision and recruiting and retaining adequate levels of staff to provide this service.

Best Practice Example

Age Concern's Dementia Home Support Service in North and West Belfast provides specific support programmes for older people with advanced dementia, enabling them to live at home. The service includes administration of medication and personal and social support and offers continuity of care, with the staff member being linked with the person with dementia at the initial assessment stage and then providing any follow-up support required.

6.32 Domiciliary support, to be effective, must be available when it is needed. Carers report particular pressures at night, often resulting in frequently interrupted sleep. This is often cited as a reason for carer breakdown and a precipitating factor in the admission of the person to residential or nursing care. Some Trusts have developed Mobile Night Services which provide support to people who require assistance going to bed, medication, toileting or security during the night. Such schemes have facilitated greater numbers of people with high level needs to remain at home.

6.33 Carers within the public consultation highlighted the potentially intrusive nature of domiciliary care and the need therefore for continuity and consistency of care.

RECOMMENDATIONS

15. Specialist domiciliary care services for older people with mental health issues should be developed. These should be available over a 24-hour period. Continuity of service delivery is vitally important and every effort should be made to ensure this is central to any new care plan.

16. Good quality domiciliary care requires adequate resources to be made available to attract good staff and allow for proper training. Trusts must identify the appropriate resources to develop specialist domiciliary support services. These services must be supplemented by assistive technology and multi-disciplinary crisis/rapid response.

Key Considerations

- Domiciliary care needs to be developed as an attractive job with career development opportunities. A regional approach to the development of the domiciliary workforce should be adopted, supported by a realistic costing of the delivery of sustainable Home Care Support services.

- Demographic trends indicate that there will be a significant increase in numbers of older people presenting with dementia and mental health issues requiring domiciliary support. This needs to be reflected in service and development planning and adequately resourced.

Emergency Care

6.34 Most older people with mental health issues continue to live in the community. Many live alone and depend on support from family and other carers. Many of the services provided are not available outside normal working hours. A problem may arise, either because of an exacerbation of illness or problem in their personal or social situation. There may be a sudden increase in risk of self-harm, harm to others, self-neglect, risk taking behaviour or sudden change in their support system. In people with dementia, a sudden worsening of the mental state is often due to a delirium caused by some underlying physical health problem, such as infection, drug toxicity or heart problems. It is essential that assessment of these individuals includes a full urgent medical examination and this is likely to be best provided through primary care.

6.35 Carers report a lack of responsive and flexible support to allow them to continue to care in their own homes safely at these times.

6.36 The change in “Out-of-Hours” GP care means that it is very uncommon for the doctor seeing the patient to know anything about the situation or background of the patient. This often makes hospital admission more likely.

6.37 Managing the person at home will nearly always be the preferred option and while some older people will need admission to hospital for treatment of their condition, it is important that they are not admitted solely to ensure their safety when, what is really required is an urgently increased level of care in the community. Community based services should be able to provide urgent assessment of their social needs and have immediate access to a range of support services, both at home (including care at night) and in residential facilities. The use of patient/carer held case notes documenting essential information, including key worker, medical issues and medication would help facilitate this.

6.38 In some parts of Northern Ireland, initiatives on chronic disease management are being piloted. These aim to develop new ways of thinking about chronic disease, in particular case management for the most frail elderly people. The literature in chronic disease management argues for joint approaches at a local level and consideration to setting up clinical directorates that span primary and secondary care, based on a clinical governance approach, information sharing and joint working. The Review sees merit in considering integration of services for people with dementia and severe FMI with future development of chronic disease management programmes.

6.39 The Review notes the development of crisis and home treatment services within general adult mental health services in a move to reduce hospital admissions, e.g. Home Treatment/Crisis Response Teams. These teams are well placed to include older people suffering from functional mental illness.

6.40 There has also been a range of developments in relation to Rapid Response Services. Again these teams are well placed to include people with dementia.

6.41 In extending these services to include older people with mental health issues, it is imperative that staff are given appropriate training to enable them to effectively meet the additional care and supervision needs of this service user group.

Best Practice Example

Ireland Lodge Resource Centre, Brighton. Provision of a crisis response team to deal with acute problems/carer breakdown in the community.

RECOMMENDATIONS

17. Support for older people with acute mental health issues should be available on a twenty-four hours a day, seven days a week basis. Support should be available both for those with dementia and functional illness.

18. A person with dementia in the community who develops acutely increased confusion/agitation should have an urgent medical assessment to check for delirium.

19. Older people should only be admitted to hospital if their medical or psychiatric condition requires it. No-one should be admitted to hospital solely to provide a place of safety when what is needed is an increased level of care in the community.

20. Older people with dementia and FMI should have access to similar crisis/home treatment teams as younger people with mental health problems or those with physical illness. Crisis/Rapid Response Services should include older people with FMI and dementia and be sensitised to their specific needs.

Key Considerations

- The use of patient/carer held case-notes documenting essential information, including key worker, medical issues, medication should be introduced.

- Consideration should be given to integrating services for older people with dementia or severe functional mental illness with future development of chronic disease management programmes.

Direct Payments

6.42 Direct Payments allow service users or their carers to purchase their own care and provide greater autonomy for individuals. Take-up levels are however low. Carers consulted identified the unwelcome responsibilities of being an employer and also the difficulties associated with finding staff to provide care.

6.43 It is important to note that care purchased through Direct Payments will not be subject to the Care Standards or Registration and Regulation requirements. Alternative safeguards will therefore need to be considered for individuals who purchase their own care.

Key Consideration

- People who choose to purchase care through the Direct Payment scheme must be offered some protection. Minimum standards of care should be established and monitoring arrangements developed.

Day Time Support/Respite Care

6.44 People with dementia have been found more likely to use day care services than other older people, particularly by those with severe dementia and those with co-resident carers (Philip et al. 1995; Moriarty and Webb, 2000). Services provide an opportunity for support, respite, therapeutic intervention, maintenance and social integration, as well as respite for carers. It is often highly valued by individuals and their carers (Levin et al. 1994; Moriarty and Webb, 2000), but is not always widely accessible. Opening hours are usually not sufficiently flexible to allow a carer to continue working.

6.45 A range of models of day care for older people with mental health issues exist, including generic and specialist community based day care settings as well as that provided within residential or nursing care homes. There is some evidence to suggest that in generic day centres, people with dementia are often not accepted or are marginalised (Curran 1996). Some generic day centres do, however, cater specifically for people with dementia by designating certain days for their attendance or providing separate facilities within the same building. Where day care is provided within residential or nursing care homes, there is some evidence to suggest that it is more acceptable to attendees, as well as to the existing resident group, if this is provided separately (Pickard, 1999).

6.46 Existing models of day opportunities tend to be very traditional and are much less likely to be based on principles of social inclusion than services provided for younger groups (Harding, 1999). The concept of “day care without walls” i.e. support provided within the community or mainstream community services needs to be further explored in relation to older people with mental health issues. The provision of day care at home should also be considered.

Best Practice Example

The Joint Dementia Initiative in Scotland has developed the “Home from Home” day care project where trained and approved local carers, working in pairs, open their homes to groups of three to six older people once or twice a week, providing company and activities in a domestic environment, with an emphasis on person-centred care. An evaluation of this model (Mitchell, 1999) found that people with dementia seemed to feel more in control and were more likely to believe that they could make things happen.

RECOMMENDATION

21. A range of models of day-time support which are responsive to user and carer need and which promote social inclusion, should be developed. Particular consideration should be given to people in rural settings and the need to develop creative responses to their needs.

Respite Care

"It shouldn't be too much to ask that I get the help I need - at the time I need - to care for my husband"
Carer in relation to poor availability of respite care

6.47 Respite care is the provision of care for a period of time, in the home, in a day care facility or care home, by people other than the primary caregiver, to give the primary caregiver respite from their care giving responsibilities and hopefully ameliorate to some degree, the stresses associated with being a caregiver (Cameron and Lee, Cochrane Review Protocol, 2004). The nature of delivery can be planned, offered on a crisis basis or offered on demand of the carer (RCPsych, 2005).

6.48 Respite care is considered to be critically important in providing much-needed breaks that allow carers to continue caring, even though there is limited evidence of efficacy in achieving stated goals (Lawton, 1989). It has been found that caregivers often perceive that respite care provides benefits of self-care and relief to themselves at the expense of the safety and comfort of their family members during respite care episodes (Perry, 2001; Gilmour, 2002). There often tends to be concern about the impact of residential forms of respite, including disruption of routine.

6.49 For respite care to be effective, it needs to be accessible, flexible responsive to needs and provide good quality care (Briggs and Askham, 1999). It also needs to be a positive and beneficial experience for the older person.

6.50 Respite provision is patchy across Northern Ireland. The public consultation highlighted gaps in domiciliary based respite care in particular, including night time care. There is a need for a broad range of respite services to be established which provide carers with real relief. Service providers consulted also highlighted the potential in exploring “foster-care” models of respite. Trusts should consider appointing a designated co-ordinator to work in partnership with the voluntary sector to stimulate the further development of day time support and respite care in community settings.

RECOMMENDATION

22. Respite care provision should be a clear and identifiable part of any commissioning or service planning process. A range of models should be delivered. It should be provided locally, be flexible, responsive and of benefit to older people with mental health issues and their carers.

Housing

Introduction

6.51 Housing is referred to in People First (1991) as the "cornerstone of community care", yet its potential to either enable or prevent older people to remain living in their own homes is often underestimated. Poor housing conditions for people with additional needs can inhibit their ability to function and can add unnecessary stress on them and their family units. Conversely, well-designed, age-appropriate housing has been linked with providing optimum physical and mental health (Biggs S. et al. 1999; Blackman et al. 2001).

Current Provision

6.52 Most older people express a wish to remain in their own home for as long as possible (Burholt, 1997) yet much contemporary design remains ill-suited to frail older people and, in particular, people with dementia. The public consultation also highlighted the waiting times involved for housing adaptations.

6.53 In Northern Ireland, the majority of housing which has been provided for the home ownership market (the private sector) has been designed along very traditional concepts. Only in recent years have the needs of vulnerable people begun to be catered for, with the development of supported housing models and lifetime homes. The term "lifetime" homes refers to a home which will suit a person throughout their lifetime, so that they are not forced to move by having to overcome barriers in the dwelling. In Northern Ireland, lifetime homes standards, incorporating 17 specific design features, have been adopted in the social housing sector since 1998. These standards do not, however, incorporate any dementia-specific design features.

6.54 Despite these exceptions, housing options for people with dementia remain limited. There is also very little specific housing provision for older people who have experience of functional mental illness.

Future Planning

6.55 Future planning must allow for a wider range of housing options for people with dementia. While many people with dementia will remain in their own homes, there needs to be a choice of supported self- contained dwellings which are both domestic and homely and a choice of small group settings for those unable to live independently, but for whom a large nursing or EMI unit would prove unsuitable. The Dementia Policy Scrutiny Report (1994) recommended units for between 8-10 people in a group living environment recognising that people with dementia need to see staff and be able to contribute to domestic chores to enable them to feel relaxed and comfortable.

6.56 Older people with functional mental illness should be afforded the same rights as any other older person with equitable access to housing solutions to meet their needs. Housing provision should include floating support, home support/personal care services and supported living accommodation.

6.57 Future design of housing for older people with mental health issues must recognise, not only the particular needs of this group, but also the needs of their carers. Two-bedroomed accommodation should be developed as standard to provide individuals and their permanent or temporary carers adequate space and privacy. All property should be constructed to a "Secured by Design" standard to ensure maximum security and safety.

6.58 Housing must be designed to be suitably flexible to adapt to an individual's changing needs, with the capacity to accommodate daily living equipment and assistive technology that can be installed when necessary.

Best Practice Example

St. Paul's Court in Lisburn, a Choice Housing Association Scheme, which provides 15 self-contained dwellings with a minimum of two bedrooms and communal facilities within a secure environment. The model has been designed to promote social interaction.

Assistive Technology

6.59 Assistive technology is defined in research for the Royal Commission on Long Term Care as:

> "an umbrella term for any device or system that allows an individual to perform a task they would otherwise be unable to do or increases the ease and safety with which the task can be performed" (Tinker A. et al. 1999).

6.60 Assistive technologies range from simple low-tech items, like automatic clock-calendars to sophisticated sensor technology which detect movement or departures from usual patterns of behaviour.

6.61 Many people with dementia face difficulties and challenges in managing practical tasks and in maintaining their own health and safety. This can, at times, compromise their dignity and independence. Assistive technology provides a real opportunity for individuals with dementia to maintain a level of independence and to be supported in a less intrusive way. Recent developments in assistive technology are providing new solutions to some of the needs of people with dementia and their carers. One study (Northampton "Safe at Home" Project, 2002) found that use of assistive technology reduced carer anxiety, helped maintain existing levels of independence of the person and reduced some of the behaviours which had been giving carers most cause for concern.

6.62 It must be acknowledged, however, that assistive technologies may not provide solutions in themselves, but are or can be, an addition to the raft of support and solutions that are available. It must also be recognised that the use of assistive technology may not be appropriate for everyone with dementia. Each individual has their own experiences and contexts which require a person centred approach to finding the best way forward.

6.63 Any assessment for provision of assisted technology must take into account ethical considerations (Marshall, 2000). The views of all the people involved in the proposed actions should be considered. The Social and Technological Response to meeting the needs of Individuals with Dementia and their carers Report (ASTRID, 2000), suggests that four principles can be applied in these considerations:

- respect for autonomy;
- beneficence (doing one's best for the person);
- non-maleficence (not harming the person); and
- justice.

6.64 Where the technology is intended for direct use by the person with dementia, it needs to be designed to take account of the nature of the condition, e.g. impaired memory and learning. It is also important that any devices blend in as far as possible with the user's natural environment

6.65 Assistive technology may also be of benefit in the care of older people with functional mental illness, for example in monitoring high risk situations or providing prompts to take medication. The potential for use of assistive technology with this group has not been adequately explored or exploited.

Best Practice Example

Sydenham Court in Belfast, which provides fifteen flats for people with dementia within a shared complex. Each tenant has an individually tailored monitoring package which produces an alert if a normal lifestyle pattern is broken. Staff are then on hand to assist as required. This facilitates a non-intrusive support service. The technology also has the capacity to monitor a range of movements/activities e.g. frequency of getting out of bed at night and can adjust levels of assistance provided accordingly. This allows for the early detection of deterioration in people with dementia and more timely intervention. Within Sydenham Court, this has resulted in a very small turnover of tenants as most can be accommodated by a flexible support service which is responsive to their changing needs.

RECOMMENDATIONS

23. Providers and commissioners must contribute to NIHE strategic planning in order to ensure that the needs of the increasing population of people with mental health issues are fully considered. Future planning must guarantee a range of housing options, internal design solutions, adaptations and use of assistive technology which promotes people's independence both in their own homes and in supported housing settings.

24. Providers must ensure that support models promote empowerment, independence and social inclusion.

25. Department for Social Development (Housing Division) funds should prioritise the provision of 2 bedroom bungalows for one person in order to encourage a carer and/or family to live with the individual on a permanent or regular basis (including overnight and weekend stays).

26. Assessment processes should include consideration of the potential to use assistive technology. The use of assistive technology should be promoted and extended. This will require adequate resourcing and clear assignment of budgetary responsibility.

Key Consideration

- Supporting People monies should be identified for maintaining older people with mental health issues as independently as possible in the community.

Nursing and Residential Care Homes

Introduction

6.66 A number of older people with mental health issues will find themselves in a nursing or residential home at some point in their illness. Several studies suggest that the proportion of older people in care homes with dementia is at least 60-70% (Mann et al. 2000). Specialist provision for people with dementia is provided in “Elderly Mentally Infirm” (EMI) homes, although it is important to note that people with dementia have a range of needs and for many people, these can be met within generic care homes. Similarly a proportion of people with severe FMI may require the support of a care home. Functional Mental Illness is common in care homes and, in particular, depression, which has been estimated at around 40% (Mann et al. 2000). These high levels of mental health needs in care homes have implications for staff training.

6.67 While the aspiration of service users and carers to remain at home can and should be accommodated by the provision of a range of supported housing and community care services, for some people, there will come a stage when the complexity of their needs demands a more intensive support package which can only be met in a residential or nursing care setting. Any care continuum developed for older people with mental health issues therefore needs to incorporate this type of provision.

6.68 The crisis-led nature of many admissions to care homes can often result in a rushed decision, with a person being inappropriately admitted to a care setting without being afforded the time to consider and try out alternatives. It is important that procedures are put in place to ensure that assessments for long-term care are, as far as possible, made in an environment which is familiar to the person and afford sufficient time to allow alternative options to be explored and where appropriate, tested out. Long-term decisions should not be made at time of crisis or in an inappropriate setting.

6.69 The disruptive effect of moving residents from one care home to another as their illness progresses was also highlighted very strongly within the consultation exercise. There was strong support for the development of settings which are able to provide a continuum of care for the person throughout the course of their illness.

Care Practices

" I wish staff in the home would stop talking to my mother as though she is deliberately difficult - she is ill - she has Alzheimer's - she can't help it"
daughter of resident in care home

6.70 While it must be acknowledged that the service provided by many care homes is excellent, there are, however, a lot of issues in respect of the quality of care provided within this type of setting. This was very evident from the number of concerns raised by carers, voluntary organisations and service providers during the consultation process. Some of the views expressed included:

- the routinised and programmed nature of daily life and the need for a more person-centred approach;
- the need to provide appropriate and accessible activities for stimulation;
- the need for more individualised care; and
- building design needs to be in keeping with the needs of the person with dementia.

6.71 The Joseph Rowntree Foundation in their research study “Designing and Managing Care Homes for People with Dementia”, March 2002, sets out principles for the management of care homes, including care practice. Their research identifies best practice, including:

- staff should communicate with residents in every aspect of life in the home;
- appropriate activities for residents should be facilitated;
- palliative care should be available when necessary;
- residents’ links with their local community should be maintained as far as possible; and
- a good balance between the protection of residents and the quality of life gains that come from taking some risks should be struck.

Person–centred Care

6.72 Best practice suggests that a personal history should be taken on the admission of each resident, to build up a picture of who the person is, what his or her life experiences have been, what their likes and dislikes are and the things they value. Family and friends, as well as staff who have worked with the individual in the community, should be involved in putting this personal history together, as well as the person themselves. This should form the basis of a person-centred care plan. The availability of this personal history is especially important where the individual is no longer able to communicate easily themselves. All people living in care homes, whether they have dementia or mental health problems, or not, should be treated with dignity and respect and be valued for who they are and for their past life and experiences.

Staffing

6.73 To ensure that a high standard of care is provided, it is essential that care homes have adequate staffing levels with appropriate skill mix. The level of physical care and supervision often required for people with mental health issues, particularly dementia, can be intensive and it is essential that staffing ratios reflect such demands. The Residential Care Homes Regulations (Northern Ireland) 2005 require that “at all times, suitably qualified, competent and experienced persons are working in the home in such numbers as are appropriate for the health and welfare of the residents”.

6.74 Throughout the consultation process, service users and carers highlighted the need for "continuity of care" and "commitment from staff to be there". The role of the manager within the care home was seen as pivotal in ensuring there are shared values, commitment to residents, good communication and support and recognition for staff.

6.75 The need for on-going training in the care of older people with mental health issues was also seen as critical. Dementia Care Mapping, a tool which provides a way to measure the quality of interactions within care homes, can be a useful, if expensive, staff development aid.

6.76 There is also a need to ensure that informal carers should be enabled, if they wish to continue, to input to the care of the resident. Some carers described being "prevented" from playing a part in the care of their relative.

Access to Primary and Community Care Services

6.77 Often, once a person is admitted to a care home, he or she does not receive any further review from a doctor, unless a problem occurs. Medication is not always routinely reviewed. Residents of care homes should have the same access to primary and community care services as those living independently. This should include access to Allied Health Professions, dental and optical services, rehabilitative services and regular medical review by a GP, including review of medication.

6.78 Community pharmacists may be well placed to extend their current role of supply to further advise re: effects and interactions of medication and to offer regular review. In the USA, nursing homes are required by law to employ a consultant pharmacist to review medication every 1-3 months.

6.79 In a randomised controlled trial, Furniss et al. (2000), concluded that a brief medication review from a pharmacist reduced the amount of medication overall, with no detriment to the mental or physical functioning of the residents. In a Northern Ireland survey of pharmacists (Schweizer, 2004), 75% of all respondents stated that they wished to be more involved in providing services to care homes.

Use of Medication

6.80 A number of studies (McGrath and Jackson, 1996; Passmore et al. 1996) have indicated high levels of prescribing of sedative drugs in residential and nursing homes. This trend may be reducing as more information about the adverse affects of such drugs has become available. Sedative drugs play a modest part in the management of severe behavioural difficulties in homes. They should not, however, be a substitute for skilled management of the situation and non-pharmacological strategies should always be tried first. A behavioural assessment should be completed in an attempt to identify triggers to reduce or alleviate behaviour, before medication change is considered as often a person's behavioural change can be due to a reaction to their environment or physical ill-health or pain. Nurse behaviour therapists, where available, or clinical psychologists, can assist in this practice. Sedative drugs, where used, must be regularly reviewed.

Restraint

6.81 Older adults with dementia have the highest risk of all individuals of being restrained while being cared for (Cotter and Evans, 2003). At particular risk of restraint are those individuals whose behaviour is judged to be "unsafe", i.e. contributing to falls and interfering with treatment and/or medical devices. Restraint can be physical, chemical or environmental. Restraint is not just an issue in care homes but across settings, in both the community and hospital.

6.82 The use of physical restraint in older adults is associated with poor outcomes such as functional decline, decreased peripheral circulation, pressure ulcers, agitation and social isolation (Cotter and Evans, 2003).

6.83 Best practice supports individualised care based on knowledge about the person's usual behaviour and function that permits nursing/caring for the person safely and without physical or chemical restraint. Research provides strong support for ensuring that older people in care settings are free from restraints, for example, Neufeld et al. (1999) found that restraint reduction reduces serious injuries in nursing home residents.

6.84 It is crucial that all staff receive appropriate training and that facilities have clear policy/guidelines regarding restraint. Staff training in the use of restraint has been found to lead to significant reductions in its use (Testad et al. 2005).

6.85 The Review adopts the position that restraint should only be used in accordance with agreed guidelines and recommends that policies and guidelines are continually monitored and kept under review.

Best Practice Example

Cedarhurst Lodge Care Home in Belfast undertook in 2003 a complete review of all restraint requested and piloted a 'Minimal Restraint/No Restraint Policy" in conjunction with South and East Belfast Trust. The home has now adopted this policy in practice.

Therapeutic Activities

6.86 While therapeutic activity with older people with mental health issues should not be confined to care home settings, there is a need to ensure that residents are provided with appropriate and acceptable opportunities for interaction and engagement as well as access to counselling support. A summary of these approaches, including compensatory techniques such as reality orientation; engagement techniques, for example reminiscence therapy; life review and person-centred counselling can be found In Annex 3.

The Built Environment

6.87 Acknowledging that the care home becomes the person's home, it is important that the environment is as homely as possible, and that the care maximises quality of life. There is general consensus in the literature about the optimal physical design for care environments for people with dementia (Regnier and Pynoos, 1992; Marshall, 1997; Ministry of Health, New Zealand, 1997). Such features include the need for small homely units with many characteristics that are as familiar as possible, age appropriate furniture and fittings; obvious location of essential places, such as bathrooms, good lighting to maximise visibility and designs which provide opportunities for normal domestic activities.

6.88 The environment is known to play a particularly important role in the care of people with dementia. Parmelee and Lawton (1990) suggest that the lower a person's level of competence, the more his or her behaviour will be determined by the environment. Paradoxically, this coincides with a time when they have less influence on shaping their environment and are less likely to be able to employ internal coping mechanism to compensate for deficiencies in their environment (Holden and Woods, 1995).

6.89 A local study (Thornton and Robinson, 2000) which examined how the factors of design influenced the well-being and functional ability of older people with dementia, found that certain features of a dementia–design specific, e.g. total visual access to bedrooms, en suite facilities, use of visual cues, reduced disorientation and wandering.

Best Practice Example

Meadowbank House in Omagh, a purpose-built care home for people with dementia which provides care on a small-scale basis, i.e. three bungalows, each accommodating eight people.

Regulation and Inspection

6.90 A strong message throughout the consultation process, from service users, carers and service providers, was the need for more robust arrangements for regulation and monitoring of care homes. It was suggested that the Registration and Inspection Units had "little power over the standard of care being offered in the homes" and "that very few homes had sanctions imposed against them despite failings on their part to provide adequate care." Some carers also indicated that they were afraid to complain, feeling that "if they issued a complaint against the home, that the patient would be adversely affected."

6.91 The recent establishment of the Regulation and Quality Improvement Authority (RQIA) is timely, to ensure that the standards in all care homes are raised and that these standards continue to develop as advances are made in the care of people with dementia and functional mental illness. The RQIA alongside the DHSSPS (who are responsible for setting standards) also has a role in ensuring that care homes providing high quality care are supported to continue to do so.

6.92 Consideration should be given to the development of dementia/ mental health specific standards in relation to care homes.

RECOMMENDATIONS

Restraint

27. Organisational structures should support restraint-free/minimal restraint care and provide the required staff education, consistent staffing levels and the equipment and technology necessary to support this care strategy. Audit frameworks to monitor employment of restraint policies should be in place within all care settings. A regional directive that is dementia specific should be developed.

Primary and Community Care

28. Older people with mental health issues who are resident in care homes should have the same access to all primary and community care services as those living independently in the community, e.g. dental, podiatry and optical services, rehabilitation, falls prevention services and day care services if that is their choice. This should also include regular medical review by a GP.

Quality of Life

29. Standards of care in all care homes should reflect not only high quality nursing care, but also a culture that promotes a positive and enjoyable quality of life, including appropriate activities, enjoyable and appropriate food and promotion of independence. This should be regularly reviewed.

Standards and Staffing

30. Staffing levels should adequately reflect the high level of needs of older people with mental health issues.

31. There should be adequate induction, supervision and ongoing training for staff, particularly in the management of dementia and mental health needs.

32. There should be effective and rigorous monitoring and reporting of standards and quality, including the quality of life and lived experiences of residents, within care homes by the Regulation and Quality Improvement Authority.

User and Carer Involvement

33. Users and carers should be fully involved in all decisions about care and care provisions.

Key Considerations

Assessment

- Assessment for ongoing care and accommodation should be made, where possible, in a familiar environment in the community.

Assessment should be:

- On-going and reviewed;

- Person-centred, reflecting abilities and strengths as well as needs;
- Empowering and enabling;
- Inclusive of the person, their carers and families and supported by professionals; and
- Reflective of the person's life history.

Environment

- Care homes should provide individual, small-scale living units in a homely design, incorporated within local communities to meet the needs of residents with dementia or functional mental illness. Possibilities for providing a continuum of care within the same setting should be explored.

- Design should reflect changing needs of individuals, e.g. adequate room sizes for aids and adaptations, suitable doorway and corridor sizes to accommodate wheelchairs.

- Appropriate living accommodation to promote independence, enabling privacy to permit relative/carer involvement. Access to gardens, community amenities and accessible transport to facilitate socialisation are also vital.

Primary and Community Care

- Pilot projects of enhanced community pharmacy input to residential and nursing homes should be developed.

Standards and Staffing

- Dementia/mental health specific standards in relation to care homes should be developed.

User and Carer Involvement

- Where the resident is unable to communicate his or her views and preferences or does not have a carer to speak on his or her behalf, the services of an independent advocate should be considered.

Interim Care

6.93 Interim care challenging behaviour facilities for the relatively small number of the most disturbed people with dementia must be developed and funded according to individual need. This care must be tailored to the individual, delivered in appropriate, small, local, domestic environments by specialist mental health nursing and allied professional staff.

6.94 This care, whether delivered by the statutory or independent sector, must be multi-disciplinary in its delivery, to the same standard as that delivered by current statutory inpatient high dependency psychiatric units, with access to expert medical input. These facilities must fall within the remit of new mental health legislation.

6.95 This level of care must be available where it is needed, at a time when it is needed, for as long as it is needed, as part of the range of services provided for this small but significant vulnerable group. Recognition that this level of care will be required for a finite period as the illness progresses is necessary to ensure provision of onward nursing care, when appropriate.

6.96 Providing this level of care will have inevitable funding implications. It is important that tariffs reflect this. There will be a need for specialist, tailor-made contracts for people with very complex needs. In these situations, money should follow the need.

6.97 These facilities must be subject to robust regulation and quality assurance.

6.98 There is an equal imperative to provide interim to long-term care for those people suffering chronic disabling mental illness who are not confused. These facilities must also be small and domestic in nature and be staffed by specialist mental health nursing and allied professionals. They should also be subject to the same robust regulation and quality assurance processes.

RECOMMENDATION

34. Interim care challenging behaviour facilities should be developed. These must be appropriately staffed and funded.

Palliative Care

6.99 Patients with advanced dementia are often cared for in a nursing home. A study by McCarthy et al. (1997) found that approximately 40% of people with dementia die in residential or nursing care homes. It is important to stress, however, that it is possible for patients with advanced dementia to be cared for at home if the appropriate supports are in place.

6.100 The palliative care approach provides appropriate control of symptoms, emphasises overall quality of life, takes a holistic approach, involves the person and family in decisions and fosters good supportive communication between all concerned. Whether it is the dementia process that is the “terminal” event, or another co-existing illness, these patients have the same need and right to have their physical symptoms relieved and to receive appropriate psychological and spiritual support. Their carers also require support in the terminal phase and in bereavement. It is more difficult to assess levels of pain and other symptoms in patients with dementia, and this must be taken in to consideration. Decisions regarding intervention and the use of advance directives may need to be discussed with the patient at as early a stage in the illness as possible.

6.101 Specialist hospices for people with advanced dementia have existed in the USA for some time. These units make control of symptoms a priority and tend to limit medical interventions including tube feeding and cardiopulmonary resuscitation, which might add to discomfort without definite benefit (Balfour et al. 2003). While serving a function, these units create the further dilemma of having to move people on from their current residential or care home, which may not be in their best interest (Hughes et al. 2005).

6.102 Hughes et al. (2005) suggest that the palliative care approach for people with advanced dementia should be pursued in all community and hospital settings. As yet there is no consensus in how this should be achieved. Clear links should be established between primary care, specialist services and palliative care with regard to the special needs of older people with mental health issues towards the end of life.

RECOMMENDATION

35. Commissioners should seek proposals on how a palliative care approach for people with advanced dementia can be rolled out to all care settings.

Key Considerations

- Closer links between primary and specialist teams and palliative care specialists should be encouraged.
- Existing specialist palliative care teams should have training on the special needs of patients with functional mental illness or dementia.
- Involvement of the patient in end of life decision-making should be facilitated. Protocols may be helpful here.
- Where possible, older people with mental health issues should have the option of terminal care at home.

CHAPTER 7

CONTINUUM OF CARE - INTERMEDIATE, SPECIALIST AND IN-PATIENT CARE

Introduction

7.1 Intermediate care is a short-term intervention to preserve the independence of people who might otherwise face unnecessarily prolonged hospital stays, inappropriate admission to hospital or residential care (King's Fund, 2004). Intermediate care can involve "step up" care to prevent hospital admission in the first instance (this usually takes the form of intensive domiciliary/nursing support provided in the person's own home) or "step down" care which facilitates early discharge from hospital (this level of care can be provided in the person's own home or within a care home facility). The primary focus in intermediate care is on rehabilitation, with therapeutic input from a range of professionals.

7.2 Older people with mental health issues are often excluded from mainstream intermediate care services. This is largely based on an erroneous assumption that the potential for rehabilitation, particularly for older people with dementia, is limited. There also tends to be concern that people with dementia and more severe psychiatric disorders pose too high a risk to be managed by intermediate care services, many of which are provided in the person's own home.

7.3 Often, the criteria for acceptance on to intermediate care schemes, are service rather than needs driven, for example, the need to clearly define the time limits of the intervention and the date for the withdrawal of the service at the outset. This can prove difficult in the care of older people with mental health issues where there is perhaps more unpredictability about "recovery" timescales. There is also a lack of confidence and skills in working with this group among mainstream intermediate care staff.

7.4 The DoH "Everybody's Business" Report (2005) identifies two models which have developed in response to these circumstances:

- developing the skills of staff in mainstream services, with additional specialist support, where the primary need is for physical rehabilitation, but where there may be underlying mental health problems; and
- developing separate specialist teams or resources where the primary need is the mental health problem.

7.5 The Report identifies the essential elements of a responsive service as including:

- proactive searching for older people who may benefit from intermediate care;
- avoiding unnecessary admissions, but when that happens, enabling the older person to move through the system quickly;
- training carers and support staff to observe and recognise some of the common causes of illness that often result in hospital admission, e.g. urinary tract infection; and
- liaison psychiatry to support staff in mainstream intermediate care services who may have limited knowledge or experience of working with older people with dementia or functional mental illness.

7.6 Where intermediate care is provided within care home settings, it is important to ensure that these beds do not become used for long periods for patients who are discharged from hospital and awaiting a care package in the community or placement in residential or nursing care.

Best Practice Example

The 24-hour Elderly Mental Health intermediate care service set up in Portsmouth to provide intermediate care services for older people with mental health problems. The service gives people the choice to remain at home.

RECOMMENDATIONS

36. Older people with mental health needs should have access to suitable intermediate care services.

37. Specialist teams should provide the necessary support to staff working in mainstream intermediate care services. This may include in-reach by link staff from specialist teams to provide support, training and coaching.

Key Consideration

- Hospital and community staff should be proactive in identifying individuals who would benefit from intermediate care services.

Specialist Services

7.7 Specialist services should be available for consultation and treatment of the range of mental health issues in older age. They should provide a range of services from diagnosing and treating more complex problems, to providing community and in-patient support for those with a clinical need. The emphasis should be on promoting the independence of older people with mental health issues and their carers in the community, wherever possible and practical (NSF Older People, 2001).

7.8 Older people with mental health issues should be referred to specialist services when their needs become more complex. They should have access to assessment, information and advice and a range of health and social care interventions which will promote optimum levels of recovery, independence and quality of life. Triggers for referral to specialist services might include:

- there are diagnostic issues that need clarification;
- there is lack of response to initial intervention strategies;
- distress or risk are particularly severe;
- problems are complex; and
- legal issues require their involvement.

(“Everybody’s Business” Report, DoH, 2005)

7.9 From the user and carer point of view, the service should be seamless, with movement between mainstream and specialist care and back, occurring with minimal delay and disruption and in relation to this, clear protocols should be in place.

7.10 Users and carers value having a named/key worker (Public consultation) and anyone with a diagnosis of dementia or long-term severe functional mental illness, should have a named/key worker throughout the course of their illness. In some instances this role may be undertaken by the person's GP. Where the person's needs are not complex, the key worker role may be limited in nature and be more about the individual and/or their carer having a point of contact. Systems should be in place to ensure that it is always clear who the named worker is. This is crucial to the success of a service and is particularly important where there is a transfer of responsibility between primary and secondary care.

7.11 The Review sees merit in the development of an “enhanced practitioner role” within the specialist team, with responsibility for developing closer links with primary care. The role could involve health promotion, education, advice, therapeutic input etc.

7.12 Several innovative pilot schemes in General Adult Psychiatry, such as those in Limavady and Mid-Ulster, have been found to be effective in reducing delays in actioning referrals and in ensuring the development of timely, accessible assessment services and have been very positively evaluated by service users and primary and secondary care staff (A Strategic Framework for Adult Mental Health Services, 2005).

7.13 The enhanced role practitioner for older people with mental health issues is likely to be a senior practitioner who is part of the specialist multi-disciplinary team and obtains support and supervision there. They would work closely with generic services providing education, advice, a degree of assessment and possibly other specialist skills such as psychological treatments. They would help to ensure a seamless transfer for people between primary and secondary care and vice versa.

RECOMMENDATION

38. Anyone with a diagnosis of dementia or long-term severe functional mental illness should have a key worker for the duration of their illness.

Specialist Multi-disciplinary Teams

7.14 Specialist services for older people should be comprehensive, multi-disciplinary, accessible, responsive, individualised, accountable and systematic (NSF Older People Standard One).

7.15 The specialist multi-disciplinary team is the cornerstone of delivery of care to older people with dementia and functional mental illness within the context of specialist services. It will be firmly embedded in the locality. Core disciplines will include psychiatry, nursing, social work, occupational therapy, and medicine. It is also important to note the emergence of new roles within multi-disciplinary teams such as OT technicians, physiotherapy and nursing assistants and mental health support workers. Specialist teams have still not been established in some parts of Northern Ireland.

7.16 Clinical psychologists should also be core members of the specialist multi-disciplinary team, as recommended in the NSF Older People (2000). This service is currently poorly developed throughout Northern Ireland. A more detailed outline of professional roles can be found in Annex 5.

7.17 Teams should have an adequate skill mix e.g. bereavement counselling, psychotherapeutic expertise or specialist training in management of behavioural problems in dementia. Teams should further develop to include patient advocacy and input from physiotherapy, speech and language therapy, dietetics, podiatry and community pharmacy, all of whom should have suitable training. Adequate administration and management support is crucial.

7.18 They should work closely with generic elderly care services and primary care teams to provide a seamless, quality service. The specialist team should also have close links with a wide range of community resources across statutory, voluntary and private sectors, including day-care, day hospital, inpatient services. It will also have a significant educational and training role.

7.19 Historically, specialist teams have functioned in a variety of ways, with some holding cases throughout the entire course of the person’s illness, while others pass less complex cases on, following assessment, to generic services in primary care. While holding cases indefinitely clearly has advantages in terms of continuity, experience has shown that teams can become overwhelmed and waiting lists develop. We see the role of the specialist team as involving assessment, intervention and complex case management, together with education and training.

7.20 The Review proposes an enhanced service at primary care level with added training and support to enable these services to manage people with less complex needs. As mentioned above, this might link in with chronic disease management models. There should be clear protocols in place to support transfer of responsibility between primary and specialist teams.

7.21 The specialist team should deal with all aspects, stages and varieties of psychiatric disorder arising in older age, especially all stages of dementia (RCPsych, 2005). The key functions of the team will be to:

- provide timely information on a person’s problem, available treatment and support;
- ensure that people’s physical health needs are being addressed, in co-ordination with mainstream older people’s rehabilitation services;
- provide on-going care, support and treatment for older people with more complex mental health problems and their carers;
- ensure that carers and family members are adequately supported and that their strengths are maximised;
- provide outreach support to users of other services who have mental health problems, e.g. residents in care homes; and

- provide support, advice and training to staff in the range of mainstream organisations that provide care to older people with mental health problems, including voluntary agencies and carers' organisations.
  (based on "Everybody's Business" Report, DoH, 2005).

Staffing Ratios

7.22 In 2000, the Faculty of Old Age Psychiatry of the Royal College of Psychiatrists, produced a set of "norms" to describe basic services expected to support each Consultant Old Age Psychiatrist. These, whilst useful, were not sufficiently robust to determine service provision and as a consequence are no longer recommended as a guide to new appointments. They do, however, form a template to describe an ideal team where all other community and hospital based services are in place.

7.23 To provide a service to an appropriate standard of care, the recommendation is for 1 whole time equivalent (WTE) Consultant for 10,000 aged 65 and over. Large geographical catchment areas with high socioeconomic levels of deprivation and few supporting medical staff will inevitably increase Consultant workload, as will the extent of responsibility for those older people with enduring or relapsing functional mental illness and younger onset dementia. The effectiveness of social services and Elderly Care Medicine will also be important factors. The issue of staff ratios will be considered in further detail in chapter 9, "Making it Happen".

RECOMMENDATIONS

39. Specialist Multi-disciplinary Teams for Older People with mental health issues should be introduced where not currently in place.

40. Pilot projects which include the development of enhanced practitioner roles should be set up and monitored.

Key Considerations

- Input from clinical psychology is currently inadequate and yet is important in terms of psychometric testing and psychological help for patients and carers. Input from clinical psychology should be strengthened.
- Specialist teams should develop to include patient advocacy and input from physiotherapy, speech and language therapy, dietetics, podiatry and community pharmacy, all of whom will require specialist training in mental health issues of older people.
- The core business of a specialist team will include assessment, intervention, complex case management with education and training. To allow this to happen, investment will be required in services at primary care level to provide additional training and staff who are equipped to look after people with less complex needs.

Assessment

7.24 Assessment will take place in a range of facilities, including the person's home, the health centre, day hospital, outpatients or other facilities and it is good practice for at least part of the assessment to take place at home (RCPsych, 2005).

7.25 Timeliness is important and yet increasingly difficult as referral numbers increase with the ageing population. Teams will organise assessments as suits the local circumstances. It is crucial that the team deals with referrals efficiently and the Review sees merit in moving towards a single portal of entry for referrals, whereby referrals are dealt with at team meetings and allocated by the multidisciplinary team rather than in the traditional model, where the team and consultant work in parallel. There should be minimum duplication and any team member should be able to provide an initial assessment on behalf of the team.

7.26 Assessments should encompass the overall care situation and should consider physical, psychological, social and spiritual needs. Risk should always be considered and documented in a standard way.

7.27 Assessment will usually include a diagnosis, but not necessarily at the first contact. People with mental health issues, and, if appropriate, their carers, should be given the diagnosis in a sensitive manner, taking account of their capacity to understand and with open discussion of issues. This is an ongoing process and should not be limited solely to the initial contact. For all patients, but especially those with dementia, it is important that post-diagnostic support is available. The diagnosis will usually be given by a doctor trained in mental health problems of older people, but as services develop, could be made by another professional in the context of a well functioning multi-disciplinary team with medical input such as a nurse specialist.

Memory Assessment Service

7.28 Services for people with dementia should include a service for those who have concerns about their memory. Not all of those individuals who present with concerns will have dementia – some will have mild cognitive impairment, some depression and some no identifiable mental health problem. The main purpose of this service is the early detection and diagnosis of dementia, while identifying treatable causes of cognitive impairment. Some services run pre-screening clinics to ensure that all investigations are in place before the assessment and this may increase efficiency, e.g. Mater Hospital and Homefirst Trusts.

7.29 The service should provide pre- and post-diagnostic counselling and support where appropriate, information, risk assessment, advice on driving and medico-legal issues, support for carers, access to the full range of support services and psychological and pharmacological treatment as required. A study by Simpson S. et al. (2004) concluded that memory clinics might be less suitable, however, for patients with prominent psychiatric complications.

7.30 Service providers who participated in the consultation process, commented on the lack of local access to memory clinics and also highlighted the fact that hospital locations are not always appropriate/suitable to host memory clinics.

7.31 Many memory clinics were set up following the introduction of the anticholinesterases in 1997. The Review considers that anti-dementia drugs play an important part in the range of services available for people with dementia. Currently there is controversy surrounding, not their efficacy, but their cost effectiveness and the Review expects that a decision will be made on this in due course by CREST.

7.32 Although each case should be considered individually, in general the diagnosis of a dementia should be disclosed to the person and his or her family. The process should include a discussion of prognosis, advance planning, treatment options and available support.

7.33 There is a growing body of evidence which highlights the perceived benefits to the person with dementia of being told their diagnosis at an early stage. In a study by Pratt and Wilkinson (2003) participants identified a range of positive opportunities gained by knowing the diagnosis, including planning, accessing appropriate support and making the most of their time. They identified few limitations from knowing the diagnosis.

7.34 In practice, however, almost half to two thirds of general practitioners in a Scottish-based study, did not tell the person their diagnosis (Downs M. et al. 2002).

7.35 It is also important to note that carers may have a yet different perspective and wish to protect the person with dementia from the knowledge of their condition (Maguire et al. 1996).

7.36 Exceptions to disclosing prognosis might be severe dementia, where understanding of the diagnosis is uncertain, phobia about the diagnosis or severe depression (Patterson et al. 1999).

Best Practice Example

CANDID (Counselling and Diagnosis in Dementia) is based at the National Hospital for Neurology and Neurosurgery. They provide a clinical assessment and diagnosis to UK residents, under the NHS. E-mail support groups are provided as part of their web based resources and an interactive virtual carer support group, which allows users to talk on-line with other carers.

RECOMMENDATIONS

41. Pre- and post-diagnostic support should be available for people with dementia and their carers.

42. Consideration should be given to moving towards a single point of entry for referrals to specialist services with multi-disciplinary allocation of referrals as suits local circumstances.

Key Consideration

- The diagnosis of dementia and related information should be given in a sensitive manner, taking account of the person's capacity to understand and wish for information. Information about diagnosis will be an ongoing process.

Models of Service

7.37 The "Everybody's Business" Report (DoH, 2005) suggests that a useful concept in integrating diverse models of service, is that of the "virtual" team, where staff may not necessarily be based in the same location, but have closely co-ordinated roles. There may be core team members, for example, such as the team manager; part-time members who work in other care sectors and "associate" members who work closely with the team but whose work is generated from a range of sources.

Acute Mental Health Inpatient Care

7.38 While it is unusual for older people to require in-patient admission for treatment of their mental health problem, there will be occasions when admission is essential for purposes of assessment, treatment and rehabilitation of older people with a range of diagnoses, including dementia where they cannot be cared for in the community or other settings due to the level of care and expertise required. A number of older people will also be detained under the Mental Health (Northern Ireland) Order 1986 for assessment or treatment.

7.39 The Review recommends that provision of acute mental health in-patient care for older people should be underpinned by the following principles:

i. All older people should have equal access to healthcare provision that is timely and appropriate, determined by need without regard to age.

ii. Older people with functional mental illness, requiring in-patient care, should receive treatment in separate in-patient facilities tailored to their needs within a local General Hospital site alongside other psychiatric and acute medical wards. (Royal College of Psychiatrists, 1999). The Forget-me-not Report (Audit Commission, 2002) recommends that there should be "separate living spaces available on wards" for patients with dementia and those with functional disorders.

iii. Siting of assessment and treatment units within a local General Hospital permits ready and timely access to the full range of diagnostic and treatment services required for a population with significant levels of co-morbid physical illness.

iv. In-patient mental health assessment and treatment bed provision should be sufficient for the target population in order to avoid delay to admission or necessitate placement outside of the locality.

v. Cognisance must be taken of the fact that in-patient provision for older people with mental health issues often requires a longer total admission compared to younger people, given the complexity of their presenting complaints. This must be taken in to consideration when planning in-patient facilities.

vi. Older people admitted to mental health care should have access to an appropriate therapeutic environment with the full range of specialist mental health professionals as well as Clinical Psychology, Occupational Therapy, Physiotherapy, Podiatry, Speech and Language Therapy and complementary therapies. (NSF for Older People, 2001).

vii. Strong links are required with physicians within Medicine for Older People, Medical Assessment Units and Surgical In-patient facilities as well as Accident and Emergency (RCPsych, 2005).

viii. Older people should have timely and equitable access to Specialist Liaison psychiatry services of older people. It is of note that two thirds of NHS beds are occupied by people aged 65 years or older. Up to 60% of general hospital admissions in this age group will have or will develop a mental disorder during their admission. Such mental disorder can have a significantly detrimental impact upon the patient's recovery and ultimate prognosis. A prolonged length of stay in hospital may also arise as a consequence.

ix. Older people presenting to Accident and Emergency (A&E) departments must also have timely and equal access to 24 hour social care support and Intermediate Care provision without prejudice. Consideration should also be given to systems which could fast-track people with dementia/FMI through A&E, for example a liaison nurse or acknowledgement of dementia within the triage system.

x. It is unusual for older people to require in-patient admission for treatment of their mental health problem. Those who do require admission are likely to have very high levels of need. Wards must be staffed accordingly for the safety and well-being of all staff and users. It is essential that intensive and close supervision can be provided, where necessary.

xi. Admission to any mental health unit, whether for functional mental illness or dementia related care, must be for the appropriate treatment of a medical condition The admission must not be solely for the purpose of safety where social care needs cannot be adequately met out of hours in the community.

xii. Older people with severe mental illness requiring hospital admission should have timely access to in-patient beds in a unit functionally separate from the younger patient's unit. The trend towards a greater severity of illness in younger adults on admission can cause distress to older patients. Purpose built units for older people reduce fear, injury and discrimination on the basis of time given by mental health staff.

xiii. There should also be provision for single-sex provision within wards.

RECOMMENDATION

43. In-patient facilities for those with functional mental illness should be located within a function-specific unit for older people, alongside other psychiatric admission facilities within a local general hospital site. Strong links are required with the professional staff within the district general hospital.

Key Considerations

- Provision of hospital care for older people with mental health problems should be equitable, timely and person-centred.
- Adequate numbers of in-patient beds are required to facilitate timely access and unnecessary delays.
- Patients must have access to an appropriate therapeutic environment and the necessary professionals allied to medicine in an equitable and timely fashion.
- There should be ready access to Specialist Liaison psychiatry services for older people with mental health issues.

Treatments

" In the hospital, my mother got no physiotherapy after a broken hip because staff said that you can't help people with Alzheimer's - they won't co-operate. My mother will never walk again, all for the want of a physiotherapist who is trained to work with people with Alzheimer's. Surely a lot of people with broken hips have Alzheimer's"

son of patient after hip fracture treatment

7.40 Older people should have access to all recognised evidence-based treatments without prejudice. This should include all therapies recommended by the National Institute for Clinical Excellence (NICE Guidelines, 2006)

7.41 A holistic approach to the treatment of mental illness is to be promoted with attention to psychological therapies and other non-pharmacological treatments supported by recognised bodies, including Royal College of Psychiatrists, National Institute Clinical Excellence, British Geriatric Society in the first instance. The prescription of medication should only be necessary when initial strategies are ineffective or as a last resort. The NICE Guidelines on Dementia (2006) specifiy that people with dementia who develop non-cognitive symptoms or behaviour that challenges should be offered a pharmacological intervention in the first instance “only if they are severely distressed or there is an immediate risk of harm to the person or others”.

7.42 Acknowledgement of the significant potential for drug induced problems such as low sodium levels and GI bleeding as well as the risks associated with many drugs being taken together must be addressed when prescribing medication. Attention to dosage schedules, side effect and adverse event profiles specific to older people is necessary when prescribing medication. Preparations with the most favourable profiles are recommended.

Psychotherapy Services

7.43 Older people should have access to the full range of psychotherapeutic services (NSF for Older People, 2001). There is ample evidence for the effectiveness of non-pharmacological treatment approaches with this user group across a range of settings. Psychological interventions tailored for the treatment of mental health problems in older people have been shown to be effective (Woods and Roth, 1996; Neidhart and Allen, 1993; Knight, 1986; Woods and Britton, 1985) and also highly acceptable to older people (McGarry, Bhutani and Watts, 1997). Cognitive therapy adapted for use with older people suffering from depression has been shown to have similar efficacy to that demonstrated for younger adults (Thompson et al. 1996) as has brief psychotherapy (Mather, 2002). There was strong support for the provision of a fuller range of treatments, including psychotherapeutic interventions among carers who participated in the consultation process.

Dementia Therapies

7.44 All older patients should have access to all treatments supported by an evidence base without discrimination on the basis of age. Many different activities have been advocated to enhance well-being in people with dementia and increasing physical activity for older people has been recognised as essential within the National Services Framework, 2001. Activity therapists, of whom there is presently a marked deficit, provide an extremely valuable service within the therapeutic setting.

Day Hospital Provision

7.45 Access to appropriately staffed day hospitals with flexible opening hours for those with severe mental illness is seen as a priority. The provision of such facilities is invaluable in helping to prevent admission to a mental health in-patient facility or to aid recovery following admission. The times of opening should reflect need, 8am-8pm, seven days per week to complement day programmes. This, along with appropriate community models, will help reduce displacement from the home environment. In addition, it will assist with the reduction of the stress of illness for the patient and their carers, without prejudice.

7.46 While the term day “hospital” has traditionally been used to describe this type of provision, the service does not have to be located on a hospital site. It is likely that a range of service models will develop, based on local needs and circumstances.

7.47 Key elements of the service will include a comprehensive multi-disciplinary mental health assessment which will take account of any risk factors as well as the development of a treatment plan to include a range of individual and group based psychological interventions. Education and advice should be provided for carers and staff should also monitor prescribed medications. An outreach role to support staff in mainstream services should also be provided.

7.48 Consideration should be given to flexibly combining specialist day care and day hospital provision to enable better joint health and social care planning and a more seamless delivery of services for the service user.

RECOMMENDATIONS

44. Older people should have access to all evidence-based treatments according to need, including psychotherapeutic services.

45. Access to appropriately staffed Day Treatment Units with flexible opening hours for those with severe mental illness should be seen as a priority.

Key Considerations

- Prescription of medication should only be necessary when alternatives are ineffective. Preparations with the most favourable profiles are recommended.

- Professionals working with older people should be trained in the effects/side-effects of drugs.

- The needs of older people with disability and sensory impairment must be addressed.

Liaison Psychiatry Service for Older People in General Hospitals

7.49 As already highlighted, studies have shown that the over 65s occupy 60% + of hospital beds. Up to 60% of this population have a co-morbid mental illness. Eighty per cent of this co-morbidity is dementia, depression and delirium. This will increase as the proportion of society entering late age increases. Mental disorder in general hospitals is therefore 3-4 times more common than in the community.

7.50 Co-morbid mental disorder is an independent predictor of poor outcome. Those patients presenting with co-morbid mental health problems have increased mortality, greater length of stay, greater likelihood of developing hospital acquired complications (MRSA, falls, pressure sores) and are more likely to loose independent function leading to premature entry to institutional care.

7.51 In many instances the need for in-patient care will be as a result of physical, rather than mental health issues, with the older person being admitted to acute wards and settings.

7.52 There is also a growing body of research which highlights the deficits in care and treatment provided to older people, particularly with dementia, in acute hospital settings (George et al. 1997; Tibbs, 2001). People with dementia often become increasingly confused in hospital settings and their symptoms are often exacerbated as a result.

7.53 The public consultation exercise highlighted many concerns about the experience of people, particularly those with dementia, in acute hospital wards. There was a clear sense that staff had a poor level of understanding about the needs of the patient with dementia and that this often resulted in poor standards of even basic care and attention. This was exacerbated by inadequate staffing levels. Difficulties were also highlighted in relation to experiences within A&E, particularly in relation to waiting times. Concern was also expressed about the inappropriateness of people with dementia being cared for in mixed-sex wards. Service providers and carers also felt that staff had a poor understanding of the impact on the person with dementia of being moved around the hospital to different wards and departments.

7.54 Typically, 2-3% of elderly admissions to general hospitals are referred for a specialist psychiatric consultation. As such, older people are under-represented when comparing rates of referral in relation to bed occupancy and morbidity with that of younger adults.

7.55 There are few guidelines developed for sedation of patients who are disturbed as a consequence of mental disorder or delirium with over prescription of sedative and neuroleptic medications.

7.56 There are no psychological therapies available in the general hospital setting.

7.57 Literature shows that detection and treatment of mental disorders in older patients by general hospital staff is poor. Fick et al. (2000) in a study of general nurses, found that 75% did not understand the difference between dementia and delirium.

7.58 Studies have shown that structured intervention programmes can reduce delirium rates post-hip fracture (Inouye et al. 1999; Marcantonio et al. 2001). Antidepressants have proven beneficial in depressed patients with serious mental illness. Studies have shown reduction in length of stay, particularly for post-hip surgery patients (Evans et al.1997; Gustafson et al. 1991).

7.59 In the UK, there is neither structured training for Liaison Psychiatry for older patients, nor a coherent model or strategy for training. The majority of services are additional, reactive, providing a psychiatric assessment and advice on management, if requested, often without follow-up. As a consequence, the Liaison Psychiatrist depends on general staff to identify and refer the appropriate patients with limited contact and opportunity to provide teaching or training as to the presentation of mental illness or selection of patients for referral. The referrals are often vague without focus.

7.60 Further difficulty arises after the assessment in that the advice given is often not implemented (one randomised study showed that 50% of recommendations were not implemented, including antidepressant prescription) Holmes et al. (2002). Outcomes were shown to be no better than for standard care.

7.61 Ideally the psychiatric liaison provision for older people in hospital should be scheduled, proactive and multi-disciplinary. It should be an integral part of case working in a continuous sense. The opportunity exists to raise the profile of mental health as a co-morbidity, collaborate with general staff in shared care through involvement in joint meetings and education and training provision. Such a service should be readily accessible, responsive and effective.

7.62 The “Who Cares Wins” Report produced by the Royal College of Psychiatrists in January 2005, highlights the characteristics of a liaison mental health team, including the need for proper induction, training and clinical supervision for staff, a clinical lead and identified consultant psychiatrist with dedicated time to perform service planning and other duties and a liaison model of working for any services which offer consultation.

Best Practice Example

A liaison psychiatry for older people website, managed by the liaison psychiatry for older people research team based at the University of Leeds, has been developed to help facilitate collaboration between practitioners, researchers and others to promote improvements in the care of older people with mental health difficulties in general hospital settings. (see www.leeds.ac.uk/lpop)

Discharge Planning

7.63 The majority of people whose discharge from hospital is delayed are older people with mental health needs (DoH, 2003). Dementia is a principal cause of delayed discharge because of the complexity that having dementia plus a physical illness produces in terms of developing a good discharge plan (House of Commons Select Committee on Health, 2002).

7.64 Discharge should be an actively managed process which begins at the point of admission (DoH Good Practice Checklist, 2003). Older people with mental health issues should not be excluded from general hospital discharge policies and should benefit from the same provisions, for example, pre-set discharge dates. There should be an agreed care pathway for this patient group in place. All discharge decisions should be made by a multi-disciplinary team and there should be a named person with appropriate expertise responsible for discharge co-ordination. In some Trusts (e.g. Craigavon and Banbridge) Dementia Liaison Nurses have been employed to positive effect. Consideration should be given to replicating this post for older people with FMI.

7.65 Delayed discharges of older people with mental health issues should be monitored separately.

Best Practice Example

Down Lisburn Trust, as part of a programme run by the Department of Health, Social Services and Public Safety Clinical and Social Care Governance Support Team, undertook a project to improve the quality of inpatient experience and the effectiveness and efficiency of hospital discharge for older people with confusion from the Trust's two acute hospitals, the Downe in Downpatrick and the Lagan Valley in Lisburn. A number of developments were initiated, including use of a multidisciplinary protocol for confusion, addition of trigger questions to Nursing Admission and A&E profiles, work undertaken in relation to process mapping and patient flow, closer links with dementia services, the development of a pathway/protocol for confused patients.

Assessment for Placement in Residential or Nursing Care

7.66 The Review acknowledges that many older people with mental health issues in general hospital settings are disadvantaged by being assessed in an unfamiliar environment, often while ill and not functioning at their optimum capacity either functionally or cognitively. This often results in inappropriate placements in care. The Review supports the view that, as far as possible, older people should be discharged back home following hospital admission, with appropriate support services so that the very major decision about their long-term care is made in the community.

Long-Term Care in Hospital

7.67 The Review's position is that there should be no long-term care provided within a hospital setting. Older people with mental health issues should be discharged no later than 6 weeks after medical fitness is determined. While in-patients, they should also be subject to regular review.

RECOMMENDATIONS

46. Protocols for the management of common psychiatric conditions and referral to the Psychiatry of Old Age Liaison team should be introduced in to general and specialist hospital wards supported by education and training delivered by a dedicated multi-disciplinary Old Age Psychiatry Liaison team.

47. Care pathways for older people with mental health needs in the acute hospital setting should be developed.

48. There should be an appropriately qualified designated person to co-ordinate discharges for older people with mental health issues.

49. Where possible, decisions about long-term care should be made in the community, in a setting familiar to the older person.

Key Considerations

- Older people with mental illness in general hospital care must not be disadvantaged in terms of age, but have timely access to quality specialist mental health assessment and treatment.

- Funding of psychiatric services for older patients with psychiatric illness in the general hospital setting should be agreed between those NHS agencies commissioning the service and those receiving the service.

CHAPTER 8

SPECIAL GROUPS

Early Onset Dementia/Younger People with Dementia

Introduction

8.1 The provision of care to younger people with dementia has been patchy and variable throughout the United Kingdom. Several healthcare specialities have played a part, but no speciality has taken a lead to establish a co-ordinated policy for the development of services. They are increasingly recognised as a very needy group who present to many agencies, yet are not well served by present services (Marshall, as cited in Cox and Keady, 1998; Strategic Framework for Adult Mental Health Services, Bamford Review 2005).

Prevalence and Causes of Dementia in Younger People

8.2 Dementia in younger people is a significant problem with an estimated prevalence of 67 per 100,000 population aged 30-64 (Harvey, 1998). The causes of dementia in younger people include degenerative disorders – Alzheimer's Disease, Vascular dementia, Lewy body disease, fronto-temporal dementia; genetic disorders – Huntington's Chorea; neurological disorders – Alcohol related, MS, CJD, tumours, syphilis, epilepsy, trauma, hydrocephalus. Although Alzheimer's Disease remains a common cause for early onset dementia, there is a much higher representation of rare and unusual dementias in the younger age group compared to the over 65s.

8.3 Early onset dementia is particularly common in Down's Syndrome. 40% of people aged 50 with Down's Syndrome have signs of dementia (RCPsych, 2002). These individuals require access to specialist dementia services preferably within learning disability teams.

Current Practice

8.4 Delay in diagnosis, lack of information, absence of specialist services and the lack of support for carers on a long-term basis are a common, current experience of service users and carers (McErlean, 1999).

8.5 Users and carers may often not receive adequate services because there are small numbers in their locality. No single service has responsibility for provision, and points of entry into the health and social care system are varied. Unavailable or inappropriate services can lead to rapid breakdown of care packages in the community and early "burnout" of carers. Without appropriate services, at least half of patients require long-term hospitalisation within 5 years (Newens, 1995).

8.6 Requests from Psychiatrists of Old Age have increased with the reduction in NHS continuing-care beds and the emergence of new specific treatments for Alzheimer's Disease (RCPsych, 2002).

Needs of Younger People with Dementia

8.7 Young people with dementia tend to have a shorter life expectancy and their symptoms present in a different order than may be expected, which has implications for service delivery (Tindall, 1993).

8.8 Younger people with dementia have different needs compared to older people. It is argued that the social and psychological context for younger people is different from that for older people with dementia (McErlean, 1999). The implications of the disease for someone in middle age are different from those of someone who is nearing the end of their natural life span. There is a greater level of psychological distress such as anger and depression. The loss of independence and possible social isolation may lead to feelings of low self-esteem and depression (Woods, 1999).

8.9 Loss of social role may be more significant, e.g. giving up work. Financial problems may be more severe and loss of benefits such as pension rights may place a further financial strain on the family.

8.10 A family member may have to give up work to assume a carer role. Younger people with dementia are more likely to have dependent children and heavy financial commitments. Consequences of being prevented from driving may be considerable.

8.11 Behavioural disturbances such as wandering, agitation and aggression are usually more severe. Service users more often have complex medical and neurological problems. They tend to be more ambivalent about engaging in services and understandably do not see themselves as the same as older people with dementia. They want a separate service.

8.12 Individuals and family members may need genetic counselling. For conditions such as Huntington's Disease and some familial Alzheimer's Disease, specialist genetic counselling and support is required.

8.13 Carers also have greater levels of psychological distress reported (Keady and Nolan, 1997) with higher carer burden showing an inverse relationship to the age of the person for whom they are caring. The consequences for taking on the caring role may be greater e.g. spouse giving up work. There are greater levels of isolation for family and carer. Younger carers rate themselves more lonely and more resentful of their caring role (Fitting, 1986). Psychological and financial impact on families and children is more severe as they are often very young teenagers and even babies. They should be involved in care, yet encouraged to continue with their normal lives (ADS information sheet). Carers see themselves as very different from carers of older people with dementia and again want a separate service.

Views of Service Users and Carers

8.14 There is a lack of user involvement in service development (Cox 1998). Younger people with dementia can articulate their experiences of dementia and what they want from care and services (Beattie 2004). Increasingly younger people with dementia are insisting on their right to the diagnosis (Fearnley, 1997).

8.15 A consultation with service users and carers undertaken by Tees and North Yorkshire Trust (2000) found that service users, as well as wanting to be told their diagnosis, also wanted contact with other young people with dementia for mutual support, the ability to carry on with recreational and occupational activities and somewhere to socialise.

8.16 Carers wanted age-appropriate day care and respite, access to anti- Dementia medication, preventative service responses, an out-of-hours contact point and a single access point.

Service Proposals

8.17 All younger people with dementia, their families and carers should have access to comprehensive specialist services from diagnosis to long-term care (ADS workshop, 2003).

8.18 A service for younger people with dementia should have a number of elements:

- education and awareness raising;
- advice to and liaison with Primary Care;
- early investigation, assessment and diagnosis;
- access to neurology and genetics services;
- assessment and care planning including considerations of financial issues;
- flexible day care and alternatives;
- acute assessment inpatient facilities;
- respite care;
- intensive own home care; and
- support and training for carers – family and professionals.

Best Practice Examples

Foyle Trust, in partnership with the Alzheimer's Society, has developed a respite service for younger people with dementia, which is an activity based service determined by the person themselves.

Teeswide Young Onset Dementia Team (Tees and North East Yorkshire Trust) provide a "one-stop shop" service which aims to make organisational boundaries invisible to users. There is an open referral system to facilitate access and direct access to services that normally operate as tertiary services (neurology, neuropsychology and neuropsychiatry). There is liaison between services to co-ordinate care and pro-active monitoring of users and carers to prevent ill-health and breakdown. The service has been found to reduce the time from first symptoms to diagnosis by a year and waiting lists for diagnostic assessments from a year to two months. Levels of psychological problems in carers have also reduced over time.

RECOMMENDATIONS

50. Services for younger people with dementia should be located within either the mental health programme or older people's programme of care. There must be a clear policy in place and a dedicated lead for the planning and delivery of services for young people with dementia. Services must also be appropriately funded given the complex needs of this group.

51. There should be adequate financial support for young people with dementia and their carers to enable them to meet the extra costs of caring. Employers and the Social Security System should adopt practices which recognise dementia as grounds for early retirement and which protect a person's entitlement to pension rights and other benefits.

52. Residential respite is important for short breaks and could have links with an assessment/rehabilitation unit. There may be opportunities for joint developments with the Brain Injury service for assessment facilities, respite care and specialist units for extreme behavioural problems.

Key Considerations

- The DHSSPS should recognise the existence and special needs of younger people with dementia and require health and social care purchasers and providers to work together to develop services for them. There should be a clear statement of local policy in relation to allocation of responsibility for the population aged under 65 with dementia (RCPsych Council Report, 2000).

- Younger people with dementia should have access to a full range of assessment and support services, including acute assessment in-patient facilities, home care, day care, respite care and continuing residential/palliative care which recognise the different life circumstances and environment of younger people and their carers. Specialist counselling should also be made available. There must be support for family and carers.

- There should be appropriate education, training and information for all health and social services professionals to ensure an effective and sensitive response to the needs of young people with dementia and their carers.

- Collaboration with neurology, neuropsychology, medical genetics, neuropsychiatry, liaison psychiatry, substance misuse, rehabilitation and learning disability services is essential for establishing accurate diagnosis and the dovetailing of services. Non-statutory services are important and should be supported.

Learning Disability, Dementia and Functional Mental Illness

"I need help - I need to know what is in front of us - and I need help to do my best. Who is going to care for her later when I die."
man whose daughter has a learning disability and dementia

8.19 The Review's "Equal Lives" report points out that the numbers of people with a learning disability who will live into their sixties and seventies is increasing rapidly in Northern Ireland. Over the next 15 years, numbers will increase by 95%. Planning needs to start now to meet the needs of this group who also experience dementia and/or depression, anxiety states and other functional mental illnesses as well as the other difficulties and challenges of ageing.

8.20 Cooper (1997) for example found in her research that older people with learning disabilities have a greater prevalence of psychiatric morbidity than younger controls (68.7 v 47.9%). Rates of depression and anxiety disorders in his sample are also high and dementia is common. There are equal rates of schizophrenia/delusional disorders. Hatzidimitriadou and Milne (2005) provide other references which support this finding.

8.21 The Review has a fundamental message, which is that dementia and functional mental illness in older people need a great deal more planning and service improvement than is currently given and this is equally necessary for older people with complex combinations, which include learning disability.

Dementia

8.22 The risk of dementia for people with learning disabilities, except Down's Syndrome, is similar to the general population. Jokinen (2005) reminds us to bear in mind that older people with learning disabilities are less likely to have married, had children or had a job providing a pension.

8.23 People with Down's Syndrome are at high risk of Alzheimer's Disease as they grow older. "Equal Lives" provides tables to show that percentages for this group of people increase from 10-30% in those aged 40-49 to 30-75% in those aged 60-69 (McQuillan et al. 2003).

8.24 Clearly, awareness raising about dementia is needed among families and care staff as well as material on how to provide help in a way that maximises potential. Jokinen (2005) found in her research, that there was a lack of good practice material although she draws attention to the Edinburgh Principles (Wilkinson and Janicki 2002) and the work of McCarron and Lawler (2003) and Watchman (2003). The Scottish Down's Syndrome Association has produced some useful booklets (1995) for the relatives and staff of this group. Kerr and Wilson (2002) have produced a training guide for staff.

8.25 Early diagnosis is needed as it is for any other group with dementia. Diagnosis is often late due to lack of awareness across the board and because it can be difficult given communication and other difficulties.

Functional Mental Illness (FMI)

8.26 The Equal Lives report highlights that "between 20-40% of people with a learning disability are liable to have a mental health problem" (Parry ed 2002). There is now a considerable literature on the high risk of psychiatric disorder in people with learning disability, the majority being depression and/or anxiety. Hatzidimitriadou and Milne (2005) take the view that a significant proportion may be experiencing reactive depression to age-related physical illness and to the loss of a carer.

8.27 Moss et al. (1998) found low levels of referral for psychiatric assessment due to the challenge of identifying the problem, lack of co-operation and communication problems.

8.28 It would also seem likely that older people with learning disabilities will experience similar or greater rates of other functional mental illnesses as older people generally and again there is likely to be a failure to diagnose and treat.

Complex Needs

8.29 There is currently increasing policy interest in meeting the needs of people with complex needs. Those with learning disabilities along with dementia and/or functional mental illnesses are a prime example of people for whom our present models of service organisation fail.

8.30 This report endorses all the recommendations of the section of the Equal Lives report on older people, including recommendation 53:

> *"Arrangements should be developed to enable people with a learning disability who have dementia to access mainstream dementia service. This will include mechanisms to provide a skills boost between dementia services and dedicated disability services".*

8.31 Consistent with the recommendations of the Strategic Framework for Adult Mental Health Services report, people with mild learning disability must be given choice of mainstream and specialist learning disability services.

8.32 Dementia services and health and social care for older people with functional mental illness are also far from adequate at present and even more deficient for older people with learning disabilities. These inadequacies must be addressed. Awareness raising is a key issue in both learning disability and older people's services which should be addressed as a priority.

RECOMMENDATION

53. People with a learning disability should have access to good quality dementia care. Those individuals who develop dementia and are already known to learning disability services should remain within this programme of care for the purposes of continuity of care. "In-reach" expertise and support should be available as required. People with a mild learning disability who develop dementia should be cared for within mainstream services, if that is their choice.

Alcohol Related Brain Damage

8.33 The term Alcohol Related Brain Damage (ARBD) refers to the effects of changes to the structure and function of the brain resulting from long-term consumption of alcohol. There is a lack of information on the extent of ARBD within Northern Ireland. Most Health and Social Services Trusts will be able to identify people with ARBD in terms of hospital bed occupancy and nursing home placements, however this population is likely to be interspersed throughout several programmes of care, often without a formal diagnosis.

8.34 Research would indicate that ARBD accounts for 10% of the overall dementia population and 12.5% of dementias in people under 65. The peak age of those with ARBD is between 50 and 60 years of age (Scottish Report, A Fuller Life). Demographic trends and increasing patterns of alcohol consumption in the over 65 population are likely to increase incidence levels of ARBD.

8.35 People with ARBD present with a complex array of physical, social and emotional needs which require a co-ordinated approach across medical and social care boundaries as well as across different agencies such as housing, social security, voluntary and private providers.

8.36 The needs of adults with Alcohol Related Brain Damage are addressed within the Review's report, A Strategic Framework for Adult Mental Health Services as part of Services for People with Acquired Brain Injury or Progressive Brain Disease (Sections 6.16-6.22). This report endorses the recommendations made in that report in terms of the development of a pathway which addresses emotional, cognitive, behavioural and social need. The Review supports the view that older people with ARBD should have access to exactly the same range of services as younger people and should not be discriminated against in terms of age.

8.37 The specific needs of older problem drinkers are also considered as part of the Alcohol and Substance Misuse Report (Sections 10.1-10.10). This report highlights the need for addiction services and resources to be sensitive to the specific additional needs of the older population.

Best Practice Examples

Both Foyle Trust and the Northern Ireland Community Addiction Service (NICAS) have developed counselling and support services specifically designed for older people and their carers. These services offer domiciliary based visits and provide a range of individual based interventions. They also provide awareness raising, training and support to other professional staff working with this service user group.

RECOMMENDATION

54. A report should be commissioned to establish the extent of ARBD in Northern Ireland. This could form part of the overall scoping exercise and needs assessment proposed in recommendations 2 and 3.

Older People with Enduring or Relapsing Functional Mental Illness

Introduction

8.38 Individuals who have suffered enduring or episodic severe mental disorder in adulthood and have reached the age of 65 are often described as "graduating" from services designed for adults of working age to those designed for older people. Service users in this position are often referred to as "graduates". The Review has, however, chosen not to adopt this term.

8.39 The life expectancy of the general population as a whole has increased during the course of the last century. Indeed, this also applies to those suffering with major psychiatric disorders such as schizophrenia, bipolar affective disorder or depression, most of whom now survive into later life.

8.40 Over the last 50 years there has been considerable restructuring of mental health services, including the development of community based services and a move away from institutional care. Consequently those who would at one time have been cared for as in-patients in psychiatric hospitals must now have their needs met in other settings – in their own homes, with their family and other carers or in residential or nursing care settings.

8.41 At the same time, mental health services have been organised into specialities, such as acute adult, rehabilitation and old age psychiatry. Specialist old age psychiatry services accept the majority of people with mental health problems over the age of 65 who are referred at first presentation with mental health problems. There is, however, some variability in practice with respect to the transfer of these people from general adult sector mental health services to specialist old age psychiatry services. Of note also is the fact that within social services, older people's and mental health services are usually managed within separate directorates. This means that people who have been cared for within the mental health programme of care may be transferred, at retirement age, to more generic older people's services.

8.42 As individuals with severe or enduring mental illness grow older, their needs take on new levels of complexity, with increasing physical ill health, declining memory, social care issues and particular psychological problems relating to the ageing process itself. Some will also develop additional mental health problems as well as Alzheimer's Disease and other dementias.

8.43 These individuals are, however often "uniquely disabled by a combination of personal, social, mental and physical health disadvantage" (Jolley et al. 2004) and are often not a high priority for general psychiatry services.

General Principles

8.44 The service which offers the greatest expertise in the care needs of an individual should assume responsibility for their care. It is recognised that there are instances where a person's needs cannot be met in entirety by one service. In this instance, clear planning of an individual's care, so that areas of responsibility are delineated, is a prerequisite of effective delivery of care.

8.45 Where individuals are physically well, and do not have dementia, but are older than 65 years of age, and receiving ongoing care from general and community psychiatric (GC) services, the imperative principle is that of continuity of care. This must take preference over automatic referral at a particular age.

8.46 It is recommended that the standard cut-off age for service boundaries should be 65 for individuals presenting for the first time with psychiatric disorder. Where the person has been discharged back to primary care i.e. his/or her GP, from the GC sector at or around 65 years, only to re-present within a short time, then the arrangements for this needs to be agreed locally. Otherwise, if a substantial time has elapsed, or there are other difficulties such as cognitive impairment, perceptual difficulties or carers issues, then the referral is more appropriately made to old age services. The individual must be central to any clinical decisions.

8.47 In-patient and day care facilities should be provided according to that which best meets the individual's needs. In addition, the value of continuity of care, with existing staff, rather than age alone must be considered. This also applies after a patient's discharge.

8.48 Individuals may be assessed by one service but long term care provided by another service. The person's needs must take priority in such a case. (These principles are based on two papers published by the Royal College of Psychiatrists, 2002 and 2004).

RECOMMENDATION

55. At around the age of 65 years (or an age agreed within the local service) individuals with enduring or relapsing mental illness should have a comprehensive review of their health and social care needs. The individual's ongoing care should be provided by the team which is best placed to meet their identified needs. However, if someone has significant physical health problems, complex care requirements or significant cognitive impairment, then a transfer of care to the specialist old age service should be considered. It is important that the person's GP is kept fully informed of any transfer of responsibility.

Key Consideration

- Each Board/Trust area should undertake a survey to determine the needs of this service user group as resources should follow service demand. The funding of these services should relate to the relevant contribution of each element of the service to the total care provision. This will need to be reviewed and developed locally to ensure that service demand and need is met.

8.49 The needs of people becoming older with enduring or relapsing mental illness are also considered within the Review's report, A Strategic Framework for Adult Mental Health Services (Sections 4.61-4.62). This report endorses the recommendations made in terms of agreement of local arrangements for meeting the needs of this population, the need for transitional review and for identification of need in the population of people entering older age and their carers.

CHAPTER 9

MAKING IT HAPPEN

9.1 This Report is being written at a time of major restructuring of health and social care services in Northern Ireland. The recommendations are wide-ranging and will present challenges to both commissioners and providers of services. However, if these challenges can be realised, services for older people with functional mental illness or dementia related illnesses and their families will be radically reshaped and enhanced.

9.2 What will make this report a reality? There is a need for increased resources inclusive of buildings, finance and human resources to meet deficits in current services as well as taking into account the significant increases in the population over the next few decades and subsequent increased demand. However, there is a need to ensure that current resources are used effectively and efficiently. Therefore, there are challenges for all providers of services inclusive of statutory, independent and private sector providers, to re-configure and reshape services to meet changing demands and needs and realise these recommendations. It is not just about asking for more resources but being more creative also with what is already provided.

Strategic Framework

9.3 The Report provides a vision of services for the future that challenges commissioners and providers to ensure that:

- services for older people with functional mental ill-health and/or dementia should be provided in non-institutional settings;
- people are maintained in their own homes or appropriate domestic type accommodation;
- robust primary care and community based services are in place for everyone irrespective of geographical location;
- free nursing care at point of delivery;
- user and carer involvement is critical to service commissioning and implementation;
- within statutory provision, mental health services, irrespective of which directorate they sit within, should be a discrete sub-speciality, with a ring-fenced budget and clear protocols in place for interfacing with other programmes of care;
- the voluntary, independent and private sectors should be key providers of services;
- appropriate data collection for performance monitoring and planning; and
- information and advocacy services are embedded in service delivery.

Organisational Framework

9.4 The challenges for organisations are that:

- visionary and creative commissioning and provider organisations are required;
- good performance management and information systems in organisations are a prerequisite;

- partnership and collaborative approaches across a range of organisations are facilitated and promoted; and
- intra and inter-agency working is embedded in service delivery.

Services Framework

9.5 The challenges for services for a fast growing, ageing population that this Report has highlighted are:

- the need for flexible and responsive services that are not fettered by unhelpful bureaucracy;
- the need for a single point of entry and assessment;
- simple referral systems with good follow through so that people do not get lost in systems;
- the importance of the coordination of different disciplines;
- the necessity of audit and monitoring;
- the centrality to service provision of carer and user involvement;
- the need for seamless interfaces across professions and carers formal and informal;
- the need for information accessibility; and
- clarity on the funding of services and who pays for what.

9.6 It is not within the remit of this Report to define how services need to be structured and delivered, but rather that the aforementioned challenges should be addressed.

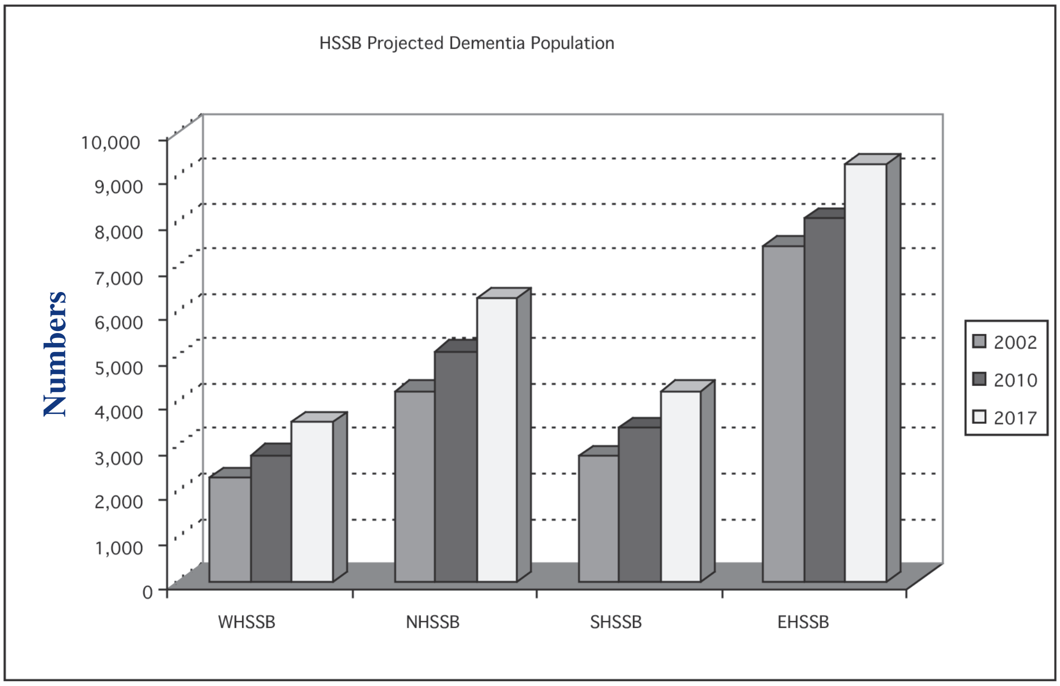
9.7 There are two key requirements to making reform happen: namely a competent workforce and adequate resources.

A Competent Workforce

9.8 In 2002 in Northern Ireland, the estimated population of people 65 + was 227,000. By 2042, this will increase to 457,000 - an increase of 98.6%. In 2002, the population of 80 + was 55,000. In 2042 this will be 156,000 - an increase of 185%. This is of major impact to planners and commissioners involved in health and social care provision.

This data can be further broken down into Health and Social Services Board projections for the next 12 years.

Summary of projected Dementia population for each Board.



(1) The Eastern and Northern Board areas will have the largest growth in the dementia population but all Board areas need to plan for the future workforce to meet this reports recommendations

Workforce Requirements

Who and How Many?

9.9 There are no norms of ratios of staff requirements per population that can be applied to ascertain workforce needs and workforce requirements. This will be determined by the types of supported living/care models of services that will be provided. The emphasis on future service provision is enabling people to remain in their own homes for as long as possible, with appropriate models of support. These should be inclusive of meaningful day activity services and home care/support or providing suitable housing alternatives that are not based on institutional living i.e. residential care homes, nursing homes or hospitals, although there will still be a need for those services.

9.10 It is also worth noting that between the present and 2025 there will be an unusually high volume of "young" old in the population. Assuming these people retire from paid employment if they can afford to do so, this age group provides a potential high rate of volunteering which will be important in community and service development initiatives.

9.11 Current service provision is delivered by a range of professional medical, health and social work staff, as well as an expansive workforce of non-professionally qualified social care/health staff - the latter of whom make up the majority of the workforce in community based provision such as domiciliary care, floating support, day centres and residential/nursing homes. With the emphasis on enabling people to remain within community settings, this section of the workforce will need to be expanded, resourced and trained to meet the increasing needs of the older population.

9.12 Significant service provision is also provided by an unpaid workforce, i.e. family carers, community groups, church organisations etc. They also require training, support and financial assistance to carry out their caring role. They are also a potential pool of skilled paid workers to recruit from. There are also opportunities to be explored in relation to using Direct Payments to make effective use of these skilled people.

9.13 The recruitment of staff within Northern Ireland will be a significant challenge and consideration will also have to be given to recruitment of staff outside Northern Ireland and Great Britain and the infrastructure required to effectively support foreign workers.

9.14 It is difficult to quantify precisely by how much the professional and non- professional workforce will need to expand without knowledge of the types of service provision that will be made available to this target population. Nevertheless, a community based approach, enabling people to be diagnosed, treated, cared for and supported in non -institutional settings will place significant demands on primary and secondary care services and require the development of increased specialist services within hospital and community settings.

9.15 A range of services for people with Dementia or Functional Mental Illness may include the following personnel:

- Consultant Psychiatrists of Old Age;
- Staff grades;
- SHOs;
- OTs;
- GPs;
- Memory Clinic personnel;
- Psychology services;
- Physiotherapists;
- Speech and Language Therapists;
- Service Managers;
- Outreach workers;
- Social workers;
- Nurses;
- Care Managers;
- Direct payment co-ordinators;
- Community care assessors;
- Social Care/Health Care workers (domiciliary);
- Residential / Supported Housing Staff;
- Floating Support workers;
- Day activity staff;
- Day Hospital staff;
- Ancillary staff;
- Specialist therapists, i.e. reminiscence, sonas, alternative therapies; and
- Drivers.

9.16 Currently many of these professionals, such as physiotherapists, speech and language therapists, psychologists, are not dedicated to older people services, yet their inputs are an essential part of a holistic treatment and care service. More memory clinics are required to ensure accessibility to these services throughout Northern Ireland and there is a general shortage of qualified nursing and social work staff to work in the area of older people with EMI or FMI. More GPs are required who are effectively trained in diagnosis of mental illness and dementia type illnesses. Many domiciliary and support services are already experiencing staff shortages. While it may be possible to apply some ratios per head of population to the provision of professional workers, it is more difficult to quantify the numbers of home care, domiciliary type workers as the model of service provision will impact on the numbers required.

9.17 Based on the recommendations of this Report, it is estimated that over the next 5 years the additional professional workers required are:

- 76.5 wte nurses Bands 5-8;
- 138 wte staff Bands 2-4 (for acute and assessment services);
- 10 wte CPNs;
- 10 advocacy workers (may be from a variety of professions;
- 5 wte Trainers;
- 14 wte social workers
- 16wte Occupational therapists;
- 7.5 wte Consultant Psychiatrists of Old Age;
- 2wte SHOs;
- 1.5 wte staff grades;
- 22 wte crisis workers (may be from a range of professional groups);
- 8 HCOs;
- 2 wte Pharmacists;
- 15wte Psychologists;
- 13wte Physiotherapists;
- 2.5wte dietitians;
- 4 wte podiatrists; and
- 15 wte speech and language therapists.

9.18 The required expansion in the non-professionally trained workforce which will make up the bulk of paid carers, is difficult to estimate. There is insufficient data about this workforce, but it is estimated that 90% of the social services workforce in Northern Ireland (36,140) are social care workers (Workforce Planning Review, DHSSPS, 2006) working in a range of settings and agencies. While this information is not broken down in to programme of care, it can be assumed, given proportional expenditure across service user groups, that the vast majority of the social care workforce is employed in older people's services.

9.19 In an analysis of one Trust's provision for a specialist Dementia/Older People FMI service (with a known dementia/FMI population of 1,475) the domiciliary work force would need to expand by at least 20% to meet projected demand, based on current service provision.

Recruitment and retention

9.20 Recruitment and retention of both professional and non-professional staff is a major concern for service providers. There are currently significant difficulties in obtaining suitable staff for care work such as domiciliary and home care and retaining them to provide consistency in service provision. This is due to a range of factors, including:

- low pay for social care workers;
- better terms and conditions and rates of pay in retail/other sectors;
- lack of career structures;
- anti-social hours and weekend working;
- inadequate travel allowances particularly in rural areas;
- lone working;
- lack of flexible working arrangements;
- differing pay scales, terms and conditions between service providers that leads to "poaching" from service to service; and
- heavy insurance premiums for use of car for business purpose particularly for under 25s.

9.21 There is a current shortage of mental health nurses and a low uptake in training programmes for mental health that will have a major impact on professional recruitment. Psychologists need to be an integral part of older people services.

9.22 Remuneration levels need to be explored across professional and non-professional staff groups but other factors also need to be considered such as:

- promoting social care as an attractive career;
- providing flexible job contracts;
- positive presentations about working with older people with mental health needs;
- provision of training and development of competences; and
- ensuring robust management and support infrastructures for all staff.

9.23 The non-paid workforce need to be encouraged and supported to maintain their caring roles as they will be a resource to recruit from.

9.24 The use of foreign workers needs to be explored and consideration given to the racial interface with the local workforce and development of appropriate infrastructures to support mobility of workers.

Training Support and Standards

9.25 The knowledge base and skills required to meet the needs of older people with FMI and those with dementia, need to be addressed for all professional and social/health care workers, as well as volunteers.

9.26 Professional training programmes in medical, health and social work courses need to address key areas of early diagnosis, assessment and treatments, which should be further enhanced by post-professional specialist training opportunities. The Centre of Excellence at the Dementia Centre, Stirling University, is one example of a provider of specialist training in working with people with dementia for all professional and non professional staff groups. However there is a lack of similar resources for older people with functional mental illness.

9.27 The social care workers of the future need to be multi-skilled in general areas of competence in working with older people and receive specialist training in the particular needs of those with FMI, depression and/or dementia. Such training must encompass the social, emotional and spiritual needs of older people, their immediate carers and family as well as physical care needs. Staff will need to develop competence in the area of assistive technologies and use of telemedicine as well as particular interventions to stimulate cognitive functioning and mental well being e.g. reminiscence therapies, creative therapies. Understanding of depression in old age, self harm, communication skills are all prerequisites of a competent workforce. There are numerous opportunities for skill development within vocational training and organisations should actively strive to embed occupational standards within management processes such as appraisal, supervision and performance management as well as enabling staff to undertake NVQs.

9.28 Service providers have a responsibility to ensure that all staff are appropriately trained and fit for purpose. The Professional Regulatory Bodies also have an important role to play in ensuring this happens. The Regulation and Quality Improvement Authority will concern itself with ensuring the competence of service providers as organisations and inspect services against clearly defined standards of practice and governance. A robust regulatory framework is essential in achieving and maintaining those standards and ensuring public confidence in all providers of services.

9.29 Service provider organisations need to support staff, especially those with direct service user contact who are often working alone. Robust, supervisory management systems need to be in place for all staff as well as sound quality assurance systems that monitor service effectiveness and ensure quality standards. Providers of services to older people are diverse and encompass statutory, voluntary and independent sectors that include paid staff and volunteers. Whether a small privately owned company or a large statutory provider, workforce and workplace competence need to be capable of effective service provision.

Resources

9.30 The recommendations in this Report provide an overall guide to required developments and outline additional resources required. More detailed analysis is, however, required to determine baseline service provision and projected service demand. Each Provider Trust will need to develop implementation plans for their resident populations and map out the services which will be required to meet identified needs.

9.31 As part of the work of the Review, a detailed costing of each of the recommendations has been undertaken. The Review anticipates that £50 million of additional income is required to implement the recommendations and ensure that the strategic framework for health and social care needs is achieved. This figure does not reflect the investment that will be required to meet demographic changes. Neither does it reflect (apart from a £5 million additional capital spend) any of the capital costs associated with reconfiguring buildings or housing costs. It is important to highlight, however, that there are likely to be some savings from reconfiguring existing services and resources.

9.32 It has not within remit of the Review to look at how additional funding is raised to meet these costs but charging for services will become a major challenge for service users. Commissioners and providers need to ensure, if introduced, fair and equitable charging policies so that primary carers are not disadvantaged.

9.33 To make this Report a reality, there needs to be additional resourcing of services but, alongside this, determination will be required, to ensure that this document does not sit on a shelf and gather dust but rather becomes a live and dynamic framework which is used to deliver excellent services to older people with mental health needs.

SUMMARY OF RECOMMENDATIONS

1. While services for older people with mental health issues may be located within either a mental health or older persons' programme of care, they should be provided as a discrete sub-speciality, with a ring-fenced budget and clear protocols for accessing other programmes of care.

2. Health and Social Services Commissioners and Providers must have in place a detailed analysis of the demographic detail of their respective rapidly expanding older populations to effectively assess need and plan for current and future provision for those older people with mental health issues. This analysis should include identification of older people from ethnic minorities.

3. Health and Social Services Commissioners and Providers should undertake a scoping exercise of current service provision for older people with mental health issues, identifying shortfalls in provision, unmet need and the service provision anticipated for the next 10 years.

4. Realistic tariffs for residential and nursing care, which reflect the particular needs of older people with mental health issues, should be agreed.

5. A Policy and Practice Development Centre for Mental Health Services for Older People should be established which would provide information, training, consultation and research and help secure comprehensive and relevant dementia service provision.

6. Public education programmes, focusing on promotion of good mental health and prevention, should be developed.

7. The DHSSPS should ensure from a strategic point of view, that health promotion in relation to mental health issues is given the same priority as for other service user groups.

8. Dementia and mental health issues in older age should be included in all training programmes for health and social care staff (including those working in the independent sector). This should be undertaken on an inter-agency and multi-disciplinary basis where possible. Training and education programmes for carers should also be provided.

9. Independent, specialist advocacy services should be available for older people with mental health issues. These should be commissioned on a regional basis to ensure equity of access and service delivery to agreed standards.

10. Health and social care professional education and training at undergraduate and postgraduate level should include more training in the area of dementia and functional mental illness. This education should include experience of dealing with these conditions in the community.

11. Primary care staff should receive more training in the early detection of dementia and

functional mental illness and recognise the benefits of doing this. The use of standard assessment tests should be encouraged.

12. Systems which are sensitive to the particular needs of carers should be in place within GP surgeries, e.g. flexible access.

13. Clear, local protocols should be drawn up jointly between primary care and specialist services.

14. Dementia care and care of older people with functional mental illness in the community should be considered as a Locally Enhanced Service (LES) within the GMS contract.

15. Specialist domiciliary care services for older people with mental health issues should be developed. These should be available over a 24-hour period. Continuity of service delivery is vitally important and every effort should be made to ensure this is central to any new care plan.

16. Good quality domiciliary care requires adequate resources to be made available to attract good staff and allow for proper training. Trusts must identify the appropriate resources to develop specialist domiciliary support services. These services must be supplemented by assistive technology and multi-disciplinary crisis/rapid response.

17. Support for older people with acute mental health issues should be available on a twenty-four hours a day, seven days a week basis. Support should be available both for those with dementia and functional illness.

18. A person with dementia in the community who develops acutely increased confusion/agitation should have an urgent medical assessment to check for delirium.

19. Older people should only be admitted to hospital if their medical or psychiatric condition requires it. No-one should be admitted to hospital solely to provide a place of safety when what is needed is an increased level of care in the community.

20. Older people with dementia and FMI should have access to similar crisis/home treatment teams as younger people with mental health problems or those with physical illness. Crisis/Rapid Response Services should include older people with FMI and dementia and be sensitised to their specific needs.

21. A range of models of day-time support which are responsive to user and carer need and which promote social inclusion, should be developed. Particular consideration should be given to people in rural settings and the need to develop creative responses to their needs.

22. Respite care provision should be a clear and identifiable part of any commissioning or service planning process. A range of models should be delivered. It should be provided locally, be flexible, responsive and of benefit to older people with mental health issues and their carers.

23. Providers and commissioners must contribute to NIHE strategic planning in order to ensure that the needs of the increasing population of people with mental health issues are fully considered. Future planning must guarantee a range of housing options, internal design solutions, adaptations and use of assistive technology which promotes people's independence both in their own homes and in supported housing settings.

24. Providers must ensure that support models promote empowerment, independence and social inclusion.

25. Department for Social Development (Housing Division) funds should prioritise the provision of 2 bedroom bungalows for one person in order to encourage a carer and/or family to live with the individual on a permanent or regular basis (including overnight and weekend stays).

26. Assessment processes should include consideration of the potential to use assistive technology. The use of assistive technology should be promoted and extended. This will require adequate resourcing and clear assignment of budgetary responsibility.

27. Organisational structures should support restraint-free/minimal restraint care and provide the required staff education, consistent staffing levels and the equipment and technology necessary to support this care strategy. Audit frameworks to monitor employment of restraint policies should be in place within all care settings. A regional directive that is dementia specific should be developed.

28. Older people with mental health issues who are resident in care homes should have the same access to all primary and community care services as those living independently in the community, e.g. dental, podiatry and optical services, rehabilitation, falls prevention services and day care services if that is their choice. This should also include regular medical review by a GP.

29. Standards of care in all care homes should reflect not only high quality nursing care, but also a culture that promotes a positive and enjoyable quality of life, including appropriate activities, enjoyable and appropriate food and promotion of independence. This should be regularly reviewed.

30. Staffing levels should adequately reflect the high level of needs of older people with mental health issues.

31. There should be adequate induction, supervision and ongoing training for staff, particularly in the management of dementia and mental health needs.

32. There should be effective and rigorous monitoring and reporting of standards and quality, including the quality of life and lived experiences of residents, within care homes by the Regulation and Quality Improvement Authority.

33. Users and carers should be fully involved in all decisions about care and care provisions.

34. Interim care challenging behaviour facilities should be developed. These must be appropriately staffed and funded.

35. Commissioners should seek proposals on how a palliative care approach for people with advanced dementia can be rolled out to all care settings.

36. Older people with mental health needs should have access to suitable intermediate care services.

37. Specialist teams should provide the necessary support to staff working in mainstream intermediate care services. This may include in-reach by link staff from specialist teams to provide support, training and coaching.

38. Anyone with a diagnosis of dementia or long-term severe functional mental illness should have a key worker for the duration of their illness.

39. Specialist Multi-disciplinary Teams for Older People with mental health issues should be introduced where not currently in place.

40. Pilot projects which include the development of enhanced practitioner roles should be set up and monitored.

41. Pre- and post-diagnostic support should be available for people with dementia and their carers.

42. Consideration should be given to moving towards a single point of entry for referrals to specialist services with multi-disciplinary allocation of referrals as suits local circumstances.

43. In-patient facilities for those with functional mental illness should be located within a function-specific unit for older people, alongside other psychiatric admission facilities within a local general hospital site. Strong links are required with the professional staff within the district general hospital.

44. Older people should have access to all evidence-based treatments according to need, including psychotherapeutic services.

45. Access to appropriately staffed Day Treatment Units with flexible opening hours for those with severe mental illness should be seen as a priority.

46. Protocols for the management of common psychiatric conditions and referral to the Psychiatry of Old Age Liaison team should be introduced in to general and specialist hospital wards supported by education and training delivered by a dedicated multi-disciplinary Old Age Psychiatry Liaison team.

47. Care pathways for older people with mental health needs in the acute hospital setting should be developed.

48. There should be an appropriately qualified designated person to co-ordinate discharges for older people with mental health issues.

49. Where possible, decisions about long-term care should be made in the community, in a setting familiar to the older person.

50. Services for younger people with dementia should be located within either the mental health programme or older people's programme of care. There must be a clear policy in place and a dedicated lead for the planning and delivery of services for young people with dementia. Services must also be appropriately funded given the complex needs of this group.

51. There should be adequate financial support for young people with dementia and their carers to enable them to meet the extra costs of caring. Employers and the Social Security System should adopt practices which recognise dementia as grounds for early retirement and which protect a person's entitlement to pension rights and other benefits.

52. Residential respite is important for short breaks and could have links with an assessment/rehabilitation unit. There may be opportunities for joint developments with the Brain Injury service for assessment facilities, respite care and specialist units for extreme behavioural problems.

53. People with a learning disability should have access to good quality dementia care. Those individuals who develop dementia and are already known to learning disability services should remain within this programme of care for the purposes of continuity of care. "In-reach" expertise and support should be available as required. People with a mild learning disability who develop dementia should be cared for within mainstream services, if that is their choice.

54. A report should be commissioned to establish the extent of ARBD in Northern Ireland. This could form part of the overall scoping exercise and needs assessment proposed in recommendations 2 and 3.

55. At around the age of 65 years (or an age agreed within the local service) individuals with enduring or relapsing mental illness should have a comprehensive review of their health and social care needs. The individual's ongoing care should be provided by the team which is best placed to meet their identified needs. However, if someone has significant physical health problems, complex care requirements or significant cognitive impairment, then a transfer of care to the specialist old age service should be considered. It is important that the person's GP is kept fully informed of any transfer of responsibility.

ANNEX I

Membership of the Dementia and Mental Health Issues of Older People Expert Working Committee

Mr Nevin Ringland (Convenor)
Chief Executive
Praxis Care Group

Dr Jim Kelly
Consultant Physician
Erne Hospital

Dr Thomas Flynn
Consultant Psychiatrist
Tyrone and Fermanagh Hospital

Ms Kate Comiskey
Manager
Blair Lodge Residential Home

Ms Kate Thompson
Director of Social Work and Primary Care
Down Lisburn Trust

Ms Marie Heaney
Programme Planner for Elderly Services
EHSSB

Dr Louise Sands
General Practitioner
Lisburn Health Centre

Ms Geraldine Brown
Foyle Trust
Assistant Programme, Older People

Sylvia Cox
Dementia Development Centre
University of Stirling

Dr Sheena Kirk
Consultant Psychogeriatrician
Ross Thomson Unit, Causeway Hospital

Ms Helen Ferguson
Carers Northern Ireland

Dr Stephen Best
Medical Director
Craigavon Area Hospital

Ms Claire Mullan
Communications Officer
Alzheimer's Society

Mr Arthur Canning
Chief Executive
Choice Housing Association

Ms Brenda Carney-Gallagher
Consultant Clinical
Psychologist
Down Lisburn Trust

Ms Noelle Barton
Assistant Director, Social Care
Homefirst Community Trust

Ms Alyson Dunn
Director of Care Mental Health
and Elderly Care
Praxis Care Group

Claire Keatinge
Director, Alzheimer's Society

Dr Hilary Henderson
Consultant Psychogeriatrican

Ms Rosemary Taylor
Planning Manager (Carer Representative)
SHSSB

Ms Helen Gilmour
Social Worker
Sperrin Lakeland Trust

Mr Joe O'Neill
Programme Manager
Ulster Community and Hospitals Trust

Ms Helen McVicker
Head of Social Work Department
University of Ulster

Ms Linda Robinson
Age Concern

Mr Ian Sutherland
Director of Mental Health and Disability
Craigavon and Banbridge Trust

Ms Anne Darragh
Ward Sister
Mater Hospital

Mr Lindsay Conway OBE
Director of Social Service
Presbyterian Board of Social Witness

Dr Jim Anderson
Consultant in Psychiatry for Older People
Ulster Community and Hospitals Trust

Kathryn Lavery
Senior OT, Dementia Team
St Luke's Hospital

Professor Mary Marshall
Director
Dementia Development Centre
University of Stirling

Mr Noel Quigley
Service Planner
WHSSB

Ms Kate Lambe
Assistant Director
Causeway Trust

(The late) Professor David Bamford
(Former) Chair of Review

Dr Brian Patterson
Chairman
NI Council, BMA

Professor Brendan McCormack
Director of Nursing and
Practice Development
The Royal Group of Hospitals

ANNEX 2

Legislative and Policy Context

Community Care

1. **People First: Community Care in Northern Ireland in the 1990s** continues to provide the policy focus for actions designed to ensure that all users of community care services have access to high quality and responsive care in the setting most appropriate to their needs. These services should optimise choice, promote independence and ensure fairness and equity.

Dementia Policy Scrutiny

2. The DHSSPS' general policy covering community care provides a policy framework that embraces dementia. However this overarching policy had only limited impact on the development of coherent dementia services. In commissioning the **Dementia Policy Scrutiny Report,** the Department sought:

   - to make good the identified policy deficit;
   - to establish a strategic direction for the development of dementia services; and
   - to provide helpful guidance on good practice for purchasers and providers.

3. A Scrutiny Action Team drawn from a variety of relevant backgrounds and professions undertook the Scrutiny from 1 March to 30 June 1994 on the basis of the following remit:

   "the policy scrutiny will review the health and social services needs of dementia sufferers and their carers, identify the components of an appropriate and effective dementia policy and make recommendations."

4. The Scrutiny Action Team's major recommendations were grounded on the need to establish dementia services on a sound and regular footing, with a clear administrative base; ensure the development of effective and well-targeted services, identifying and meeting need in a timely and appropriate manner; and contribute positively to enabling people with dementia and their carers live full and independent lives, ideally in a community setting.

5. These objectives are fully in line with the general objectives of the health and social services in Northern Ireland. The recommendations were split into two groups:

   i. those which should be implemented immediately (20 in all), generally with limited resource consequences which should be met within existing resources (including People First monies); and

   ii. those which would be implemented progressively as part of a dementia strategy, commencing now but covering the period of the next Regional Strategy (13 in all).

The latter were recognised as possibly having more substantial resource consequences.

Review of Community Care

6. An extensive consultation exercise was carried out from July to September 2001 taking on board the views of statutory and independent sector providers, voluntary organisations and the health and social care professions. The objectives of the consultation exercise were to identify barriers to the delivery of good community care services, to identify good practices across the region and to bring forward recommendations for improvements in the shorter term. **The Review of Community Care–First Report** was published in May 2002 and contained seven recommendations which were:

    1. enabling people to live in their own homes;
    2. spreading best practice;
    3. developing services to provide practical support for carers;
    4. care management processes and assessment tools;
    5. promoting the development of a flourishing independent sector alongside good quality public services;
    6. accountability of agencies; and
    7. funding structure for community care.

    A number of project groups have been set up to take these recommendations forward, including one tasked with developing a Single Assessment Tool for Older People which can be applied to all Trusts within Northern Ireland. This project is now at the start-up stage.

Carers' Issues

7. The contribution of informal carers to the effective delivery of personal social services has been recognised and the needs of carers, to help them continue in their caring role, are being addressed in a number of ways by the DHSSPS. The Minister commissioned a strategy for carers in October 2000 with the aim of identifying practical measures that will make a real difference to the lives of carers. In drawing up a draft strategy, the Department consulted a reference group of carers and organisations representing carers to find out what they saw as solutions to the difficulties carers face in carrying out their caring role. The outcome of this consultation was reported in **Valuing Carers** and was published in April 2002.

8. The **Carers and Direct Payments Act (Northern Ireland) 2002,** which commenced in part on 31 March 2003, gives carers a legal right to an assessment for services in their own right. The carer's assessment looks specifically at the impact of the caring role on the health and well-being of the carer and concentrate on what is needed to support the carer in his or her own role. The Act also makes it possible for carers to receive services in their own right and allows them to be considered for receipt of direct payments as an alternative to direct service provision.

9. The Act also places a requirement on Trusts to identify carers, to provide them with information on services available and to offer assessment of their need for services.

Protection of Vulnerable Adults

10. All Health and Social Services Boards have had policies and procedures for the protection of vulnerable adults in place since the mid 1990s, following the issuing of draft guidance by the DHSS in 1995.

11. Most policy documents have adopted the Law Commission (1995) definition of a "Vulnerable Adult", i.e. "any person aged 18 or over who:

    - is, or may be, in need of community care services or is resident in a continuing care facility by reason of mental or other disability, age or illness; and who

    - is, or may be, unable to take care of him or herself or unable to protect him or herself against significant harm or exploitation."

    The policy covers all forms of abuse and is applicable to all sectors and settings.

12. The **Protection of Children and Vulnerable Adults (Northern Ireland) Order 2003 (POCVA)** commenced in April 2005 and provides a legislative basis for the maintenance of a list of individuals who are considered unsuitable to work with vulnerable adults.

Ensuring Quality

13. **Best Practice – Best Care** (DHSSPS, April 2001) set out proposals to put in place a framework to raise the quality of services provided to the community and tackle issues of poor performance across the Health and Personal Social Services. The aim is to provide a high quality system of health and social care which is easy and convenient to use, which is responsive to people's needs and which provides a service that instils confidence in those who use it.

14. The quality agenda is underpinned by the **Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003** which has two main dimensions:

    - regulation of individual establishments and agencies; and
    - inspection of clinical and social care governance in the HPSS.

15. Key elements of the programme of change initiated by Best Practice – Best Care include:

    - a statutory duty of quality on Boards, Trusts and Agencies;
    - minimum published standards of care;
    - wider and stronger regulation of services;
    - creation of an HPSS Regulation and Improvement Authority (RQIA); and
    - links to national bodies in standard setting, training and support.

16. The RQIA will be responsible for:

- regulating services;
- conducting reviews;
- undertaking investigations; and
- carrying out inspections.

17. **A Healthier Future: A Twenty Year Vision for Health and Well-Being in Northern Ireland 2005-2025** is the new regional strategy for health and well-being and presents a vision of how health and social services will develop in Northern Ireland over the next 20 years. The five main themes addressed include:

- investing for health and well-being;
- involving people – caring communities;
- responsive combined services;
- teams which deliver; and
- improving quality.

18. The strategy places a special emphasis on promoting health and well-being among vulnerable groups, including older people, for whom preventative measures could have the greatest effect. It also offers a commitment to offering immediate access to community-based and emergency services, where these are required, and to increasing choice for people near the ends of their lives about how and where they receive services.

19. A further policy direction is concerned with protecting and promoting a “full life” for carers, people with mental health problems and older people amongst other groups.

20. The need to break down the barriers between services delivered in communities (primary and community-based care) and services delivered in hospitals (secondary, acute or tertiary care) is also highlighted.

21. The strategy acknowledges that the demands for hospital services will grow over the next years and endorses the wide-ranging programme of modernising hospitals set out in **Developing Better Services** (DBS). Two of the key directions being pursed as part of the DBS agenda are:

- greater provision of generalist services, including primary care services, within communities or on a day-patient or out-patient basis; and

- greater specialisation, particularly within acute hospital services.

22. The role of hospitals is increasingly being seen to support community based care services, requiring a whole systems approach to be adopted to ensure an appropriate balance of investment in services, both in the acute sector and in the primary and community care sectors, and innovative ways of working, which will share good practice and resources to the benefit of the patient, for example, Managed Clinical Networks.

23. **Ageing in an Inclusive Society** (OFMDFM) strategy document was launched in March 2005 as part of the Promoting Social Inclusion and Targeting Social Need initiatives. It sets out the approach to be taken by Government to promote and support the inclusion of older people in Northern Ireland. Strategic aims include the promotion of an enabling environment which gives older people choice and control over the services that influence their lives and the need for integrated action to provide more effective economic, health and housing support to the older community. To monitor the delivery of the strategy, a Champion for Older People at Senior Civil Service level has been established.

24. **Caring for People Beyond Tomorrow,** A Strategic Framework for the development of Primary Health and Social Care for Individuals, Families and Communities in Northern Ireland, DHSSPS, 2005, sets out how primary care services should be developed and provided over a 20 year time span. The emphasis is on the development of consistently high quality and seamlessly integrated services delivered in the community, close to where people live, which will provide the great majority of services, achieve high levels of health and social well-being and minimise the need for hospitalisation or residential care.

Funding Long-Term Care

25. The Royal Commission Report on Long-Term Care which was published in March 1999, recommended that the costs of long-term care should be split between living costs, housing costs and personal care, with the personal care component being paid from general taxation and the rest being subject to a co-payment according to means.

26. One of the key principles underpinning the recommendations of the Royal Commission was equity. The Report states:

> "Care needed by people with Alzheimer's Disease is directly analogous to the kind of care provided for cancer sufferers. The latter get their care free. The former have to pay…. The situation must be put right." (*para 6.33-64)*

27. While there was much initial support in principle for the Royal Commission proposals, the additional monies made available by Government were targeted more at intermediate than long-term care. Free nursing care was only provided up to a limit of £100 per week and then only if provided by a registered nurse. The House of Commons Health Committee Report (April 2005) comments:

> "Over six years after the Royal Commission reported, and nearly ten years after concerns were first raised by a predecessor Health Committee…..elderly people….still find themselves subject to a bewildering funding system which is little understood even by those who administer it, and which few patients or carers would describe as fair, or as guaranteeing their security and dignity."

28. In Northern Ireland, there has been support in principle for the Royal Commission proposals. In October 2002, the Northern Ireland Assembly introduced a weekly HPSS contribution towards nursing care in nursing homes. This payment is intended to pay for

the professional care given by a registered nurse employed in a nursing home. There is a flat weekly payment of £100, payable by Trusts to homeowners on behalf of residents with assessed nursing needs who pay privately. Alternatively, it is discounted from the charges raised by Trusts for people who are required to refund Trusts at the full rate. Those residents in a nursing home who fully fund their care may be entitled to a contribution of £100 a week towards the cost of a Nursing Needs Assessment where the client's nursing needs are identified. Any further implementation of the policy has also been delayed by the political situation in terms of the suspension of the Northern Ireland Assembly.

29. Some of the key issues which are yet to be resolved are the distinctions between health and social care and between nursing care and personal care. The definition of "personal care" adopted by the Royal Commission, which is based on an internationally recognised definition of nursing, precludes care given by other carers. This is particularly significant for older people with dementia whose care is mostly provided by informal carers and unqualified staff. June Clarke, Professor Emeritus, University of Wales, comments:

"On every issue, older people with mental health problems (especially dementia) fare worse than other older people."

ANNEX 3

Therapeutic Activities

Kitwood (1997) identifies six needs which we all have as human beings, including the need for identity, occupation and self-expression. These needs are equally important for the older person with dementia or FMI although will often need to be nurtured and facilitated by others such as carers or care staff. One way of achieving this is through offering “expressive outlets” in the form of therapeutic activities or through the use of the arts.

Activities can be linked to a person’s previous life experiences and interests or may offer new opportunities for creativity and self-expression. Occupation needs to be personally significant and to draw on the person’s abilities. Activities can target all sensory levels, which is of particular importance where verbal communication ability is impaired.

Some of the interventions highlighted below are primarily used with people with dementia; others will be appropriate for use with both dementia and FMI service user groups.

1. COMPENSATORY INTERVENTIONS

These are techniques that compensate for the level of disorientation associated with dementia.

Cognitive management and rehabilitation approaches are aimed at supporting memory function by reducing cognitive load and encouraging the use of external memory aids.

Reality orientation programmes – in these programmes, various cues and prompts are used extensively as external memory aids, to reduce load on the memory. The technique aids orientation by unobtrusively repeating facts about day to day life, current events etc. It can provide the individual with a structured environment to help them to adjust and function to the best of their ability. Environmental cues and prompts need to be obvious if they are to enhance the quality of life. The person must usually learn to associate the cue with the information its retrieval is meant to prompt. Research findings indicate that there is some evidence to suggest that reality orientation is effective in improving cognitive ability, with a demonstrable long term gain (Bates J. et al. 2004).

2. ENGAGEMENT INTERVENTIONS

These techniques use long-term memory as a means of engaging the person. Long-term memory appears to be much less affected in the early stages of dementia than short-term memory and so offers “a fertile ground for recall of past learning and past experience”(Gibson, 2006)

Reminiscence therapy involves the recollection of past activities, events and experiences with another person or group of people. This may be achieved by using tangible prompts such as photographs, familiar items from the past as well as music etc. The evidence relating to reminiscence therapy and life review is more equivocal. Positive effects were found by Baines S. et al. (1987) who found that treating confused older people firstly with reality orientation and subsequently with reminiscence therapy, led to significant improvements on measures of cognition, communication and behaviour even at four weeks post-treatment.

Recent research by McKee et al. 2005, found that reminiscence enjoyment was associated with positive psychological health while high frequency of reminiscence and regrets was associated with negative psychological health. This study highlights the need to choose participants carefully and to be aware of individual needs and differences. However, Spector et al. in their Cochrane review (2003) found there was insufficient data to reach firm conclusions about the effectiveness of reminiscence therapy for dementia and highlighted the need for further research.

Life Review/Life Story Work typically involves individual sessions, in which the person can be guided through life experiences, encouraged to evaluate them and produce a life story book. Life story material is anything that is relevant to the individual (it is not simply life history) and reinforces the person rather than the dementia.

Recent research carried out by Gibson, Haight & Michel (2006) in Northern Ireland seeks to evaluate the use of life review and a life story book project as a psychosocial intervention in long stay care settings (forthcoming publication).

Best Practice Example

The Northern Ireland Reminiscence Network, which has a membership drawn from health and social care agencies across all sectors, libraries, museums, arts, education and community organisations, encourages people of all ages to recall, share, value and preserve memories of their personal life experience for the enrichment of themselves, their families and communities. The Network undertakes reminiscence education and training, promotes good reminiscence practice with individuals and groups and engages in projects in partnership with Health and Social Services Trusts, libraries, museums, voluntary agencies, schools and colleges.

3. COUNSELLING INTERVENTIONS

Elements of person-centred counselling are used in these approaches.

Psychosocial Interventions – are the treatment of choice, in preference to drugs, in managing behaviour and mood disturbance in people with dementia. (NSF, 2001; SIGN Guidelines, 1998; Moniz-Cook, 1998; McGrath and Jackson, 1996) Awareness of the various psychosocial interventions for tackling difficult and challenging behaviour assists staff with person-centred approaches to care, thus providing a positive alternative to pharmacological therapies. This is important in the light of evidence concerning the overuse of medication in patients with dementia in nursing homes. It is essential there is a multi-disciplinary team approach with cross-disciplinary discussion of service users who present with complex issues.

Psychotherapy and Cognitive Behavioural Therapy

There have also been exciting developments in the application of dynamic psychotherapy (Hausman, 1992; Sinason, 1992) and cognitive behavioural therapy (Thompson et al. 1990) to older people with dementia. These developments reflect the earlier recognition and diagnosis of various types of dementia, resulting in a growing number of individuals with a much clearer awareness of what is happening to them.

Studies also report that CBT has produced beneficial effects in the treatment of depression and late-life anxiety (Cuijpers, 1998; Stanley and Howarth, 2003) with improvements noted not just at the post-treatment stage, but at one year follow-up.

Resolution Therapy

This therapy strives to achieve effective communication by demonstrating that people with dementia "have something to say". It entails paying attention to all attempts at communication by focusing on what is heard, seen and emotionally expressed to try to understand the world from the point of view of the person with dementia. (Stokes and Goudie, 1994). It is difficult to assess the effectiveness of resolution therapy and there is limited research in this area.

Validation Therapy

Feil developed this approach in the early 1980s. (Feil, N.1982). Feil's Validation approach is underpinned by a belief that all behaviour, no matter how bizarre, has a rational explanation, the guiding principle being that factual inaccuracies should not be allowed to impede effective communication. Various techniques are suggested, including rephrasing speech, matching the emotion displayed, linking behaviour and unstated need.

4. CREATIVE MEDIA

Art Therapies – including Dance Therapy, Art Therapy and Dramatherapy

While there is limited research on the effects of these therapies, there is optimistic belief of the benefits achieved in self-esteem, participation in activities of daily living, mobility, communication and general quality of life (Howarth and Ketteringham, 1995). Killick and Allan, 2001 suggest that fantasy and imagination play key roles for people with dementia, "allowing them to escape from the realities of predictable, institutionalised life, and providing a welcome relief from an otherwise inhospitable environment".

Best Practice Example

Elderflowers Project run by the Hearts and Minds Charity in Edinburgh – Professional actors are trained specifically in communication with people with dementia and deliver programmes using drama and humour to elicit participation and response.

Music Therapy

It has been noted by many that music occupies a special place in the lives of many people with dementia. Bright (1992) highlights that musical memories appear to be better retrieved than verbal memories, although these music memories may lead to some verbalisation. Music therapy sessions allow people to express emotion in a supportive atmosphere. They can be undertaken on an individual or group basis.

Ryszczak (2003) highlights that comparisons of music therapy sessions with discussion-led programmes have revealed significant improvements in the music therapy groups in relation to orientation, social behaviour and verbal participation, with an accompanying decrease in non-social behaviour. A study by Burke 1995, as cited by Ryszczak (2003) found that active participation in group music experiences impacted positively on self-esteem and depression in older people. Music therapy can be of benefit even to those in the advanced stages of the illness who can often seem unreachable.

Best Practice Example

"Respond to Music" Video produced by Age Concern Northern Ireland and Dementia Services Development Centre in Stirling demonstrates how music can enhance opportunities for communication with people with dementia.

5. SENSORY THERAPEUTIC ACTIVITY

This approach is aimed at sensory rather than cognitive engagement and is probably most helpful in the later stages of dementia when cognitive faculties have declined. The emphasis with such approaches is on relaxation, decreasing anxiety and improving well-being.

One such approach to emerge from the Netherlands is **Snoezelen**, which involves multi-sensory input in the form of music, projected images, bubble tubes and aromatherapy. This approach has its origins in the field of learning disability. Baker et al. (1997), conclude that multi-sensory environments led to increased happiness and interest, with a reduction in socially disturbed behaviour.

Sonas is another approach which provides a multi-sensory experience using a variety of activities to stimulate all the senses in a group setting. This therapy has been found to have a positive impact on the person's well-being both during and immediately after the group sessions (Parrish et al. 2005).

Modality Specific Stimulation targets one sense in particular, for example, the use of "white noise", which involves playing an untuned radio to people with dementia to reduce agitation or bright light therapy which has been used quite successfully for those with disturbed sleep patterns (Lyketos et al. 1999) or behavioural disturbances (Koss and Gilmore, 1998).

6. COMPLEMENTARY THERAPIES

There is a growing body of literature to support the use of various complementary therapies with people with dementia. With appropriate attention given to issues of safety and the importance of informed consent, these therapies may have much to offer when seeking to improve the sense of well-being and quality of life of both the individual and their carers.

Some examples of these are:

Aromatherapy
Reflexology
Acupuncture

Current research is limited. However, benefits reported include decreases in challenging behaviours, improved verbal and non-verbal communication and improved mental state.

7. PHYSICAL ACTIVITY PROGRAMMES

The benefits of physical activity for older people with depression are well-documented (Blumenthal et al. 1999; Singh et al. 1997). A randomised control study by Mather et al. 2001 found that 55% of the exercise group experienced a greater than 30% decline in depression. In people with dementia, physical activity has been shown to promote better sleep patterns, aid elimination and reduce constipation, help retain motor skills and reduce agitated pacing. (Tielis, infoaging.org. 2003). Physical activity can be incorporated in to the person's normal routine and should be appropriate to their general level of mobility and fitness. Even gentle exercise programmes, such as armchair aerobics can be of benefit.

Best Practice Example

"Oh dear, what can the matter be?" – a video produced by Dementia Services Development Centre, Stirling which focuses on encouraging people with dementia to stay active.

8. GROUP WORK PROGRAMMES

These may be of particular benefit to people in the early stages of dementia or for those with FMI. The group can provide a useful forum for offering mutual support, self help, advice and information or for promoting the development of new skills and coping strategies, e.g. relaxation, coping with depression or memory difficulties.

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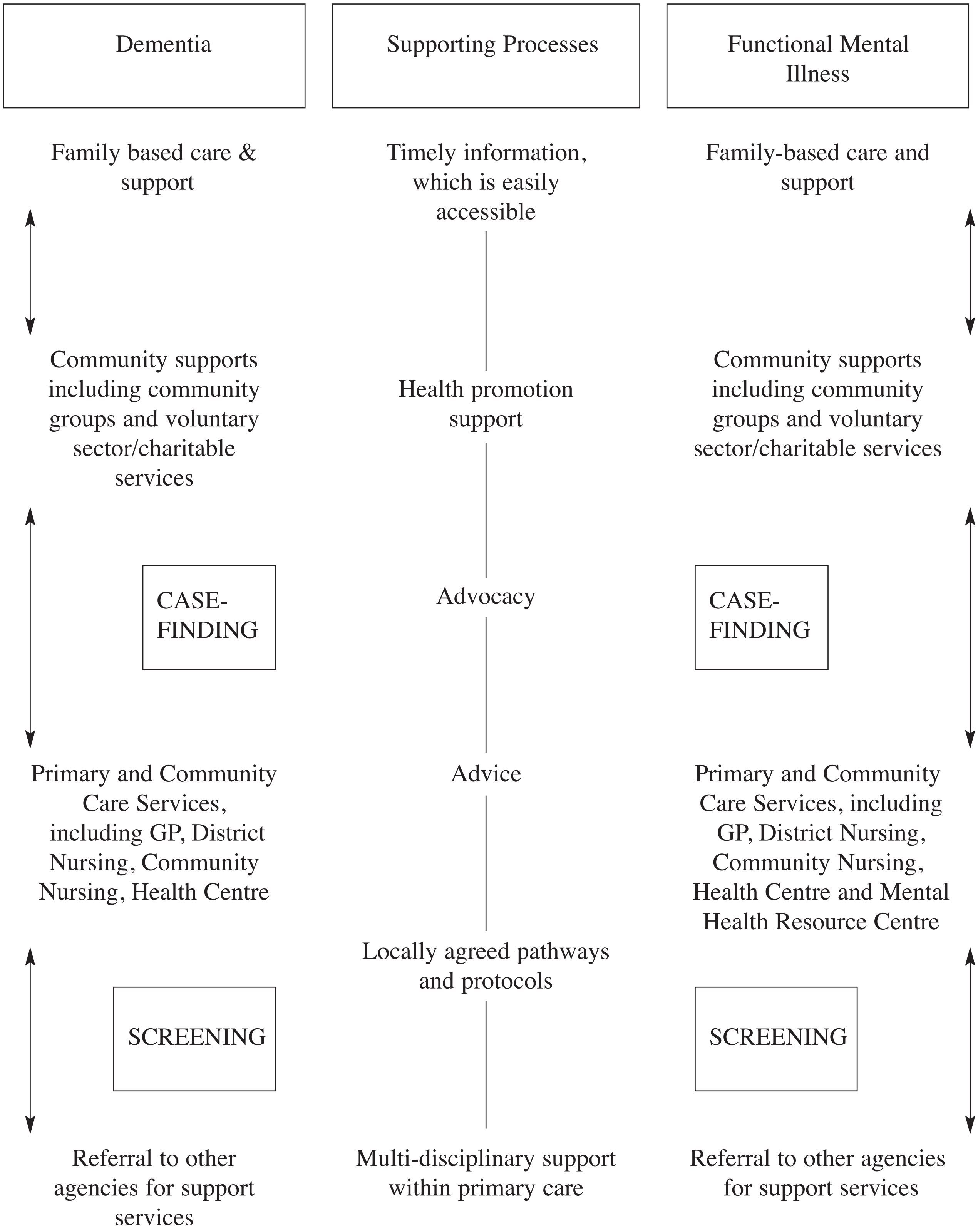
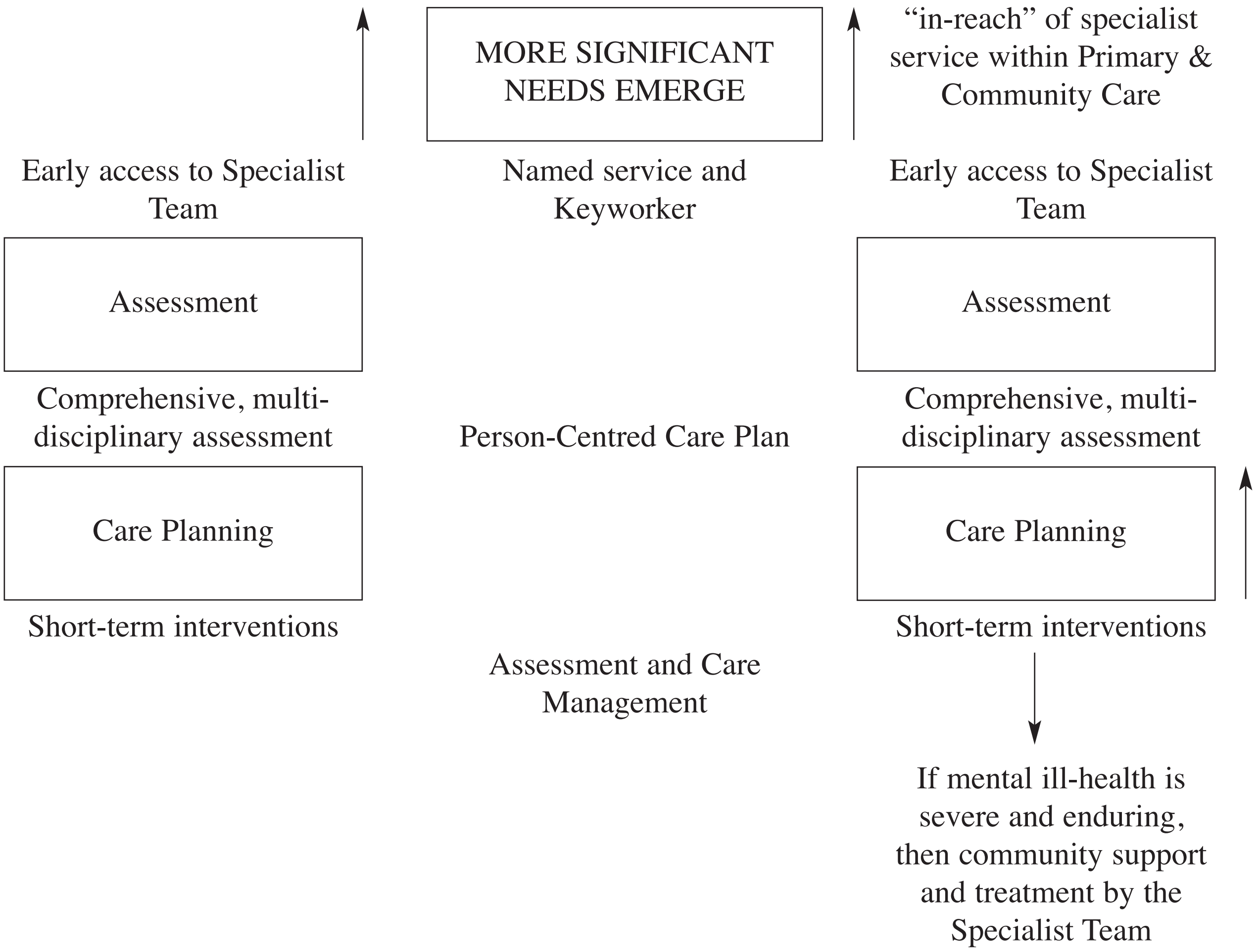
ANNEX 4

A Flow Process for The Mental Health Care System for Older People



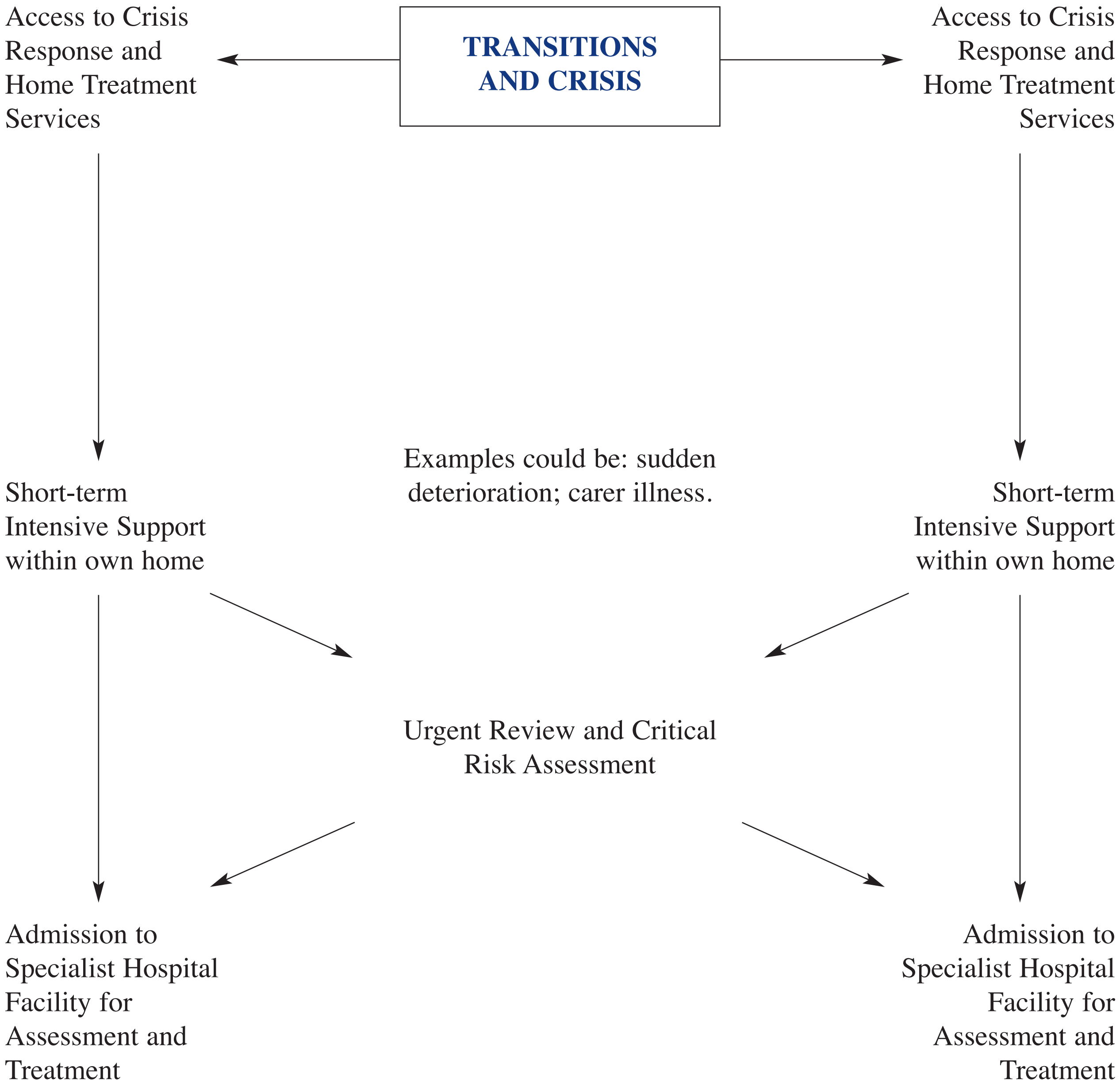
KEY ISSUES AND THEMES AT INITIAL STAGES:

- The vast majority of those presenting with depressive illness and anxiety disorders should be effectively treated and supported within primary and community care services.
- Those identified as developing dementia should be assessed and treated within primary care, with in-reach from specialist mental health services as appropriate. They should be supported at home with primary care supports for as long as possible.



KEY ISSUES AND THEMES AT THIS STAGE:

- Locally agreed protocols to support effective interface and joint working between primary and secondary care services.
- Flexible supports developed within the policy context of direct payments and personalised care budgets.
- Focus on achieving positive outcomes, effective monitoring.



COMPLEX NEEDS

- Challenging behaviour
- Unpredictability and risk
- Risk vs public safety
- “Palliative care” requirements
- Legal intervention
- Other medical conditions

- Severe and ongoing mental illness, eg Schizophrenia, Bi-polar Affective Disorder, severe depression
- Unpredictability and risk
- Risk vs public safety
- Alcohol misuse/co-morbidity
- High risk of suicide/self-harm

ANNEX 5

Multi-disciplinary Team Members and their Individual Roles in Mental Health Services for Older People, Including Dementia

Psychiatrists

Provide the medical input to the service, diagnostic and clinical expertise, treatment prescribing and assessment and information to service users and carers. They will also contribute to the development of clinical protocols and participate in research or clinical trials.

Social Workers

Provide assessment of the social situation, explore relationship issues, offer counselling support, facilitate the development of coping strategies for carers and individuals with dementia/mental health problems as appropriate, offer benefits advice. They also often act as gatekeepers to a range of support services and resources.

Nurses (including Community Psychiatric Nurses)

Nurses play a lead role in needs assessment, provide diagnostic and clinical expertise, monitor medication and provide care and support for people with mental health problems and dementia and their carers. They carry out assessments of people at home and can advise patients and carers on ways of coping and improving their health and quality of life.

Pharmacists

Pharmacists are aware of drug interactions and can advise on use of medication and possible side effects and undertake reviews of medication both for individuals in the community and in care homes.

Clinical Psychologists

A Clinical Psychologist can carry out a full neuropsychological assessment of individuals who complain of forgetfulness or who are thought to have dementia. This is sometimes warranted where the routine cognitive screening employed by Psychiatrists is inconclusive or where it reveals little in the face of considerable concern on the part of the person or their carer/family. Such an assessment will shed more light on the unique pattern of the person's strengths and weaknesses and counselling may be offered to help them explore how to cope with any apparent deficits.

Neuropsychological assessment can also help to make sense of challenging behaviours and can act as a basis for advice to those who live with and care for people who exhibit such behaviours as to how best they can be managed.

People in the early stages of dementia often suffer concurrently from anxiety or mood disorders and a Clinical Psychologist can offer psychological therapies that address these difficulties.

Occupational Therapists

Occupational therapy interventions may improve, restore or maintain function, promote participation in activities that optimise physical and mental well-being and self-care ability. Assessments are used to help establish a diagnosis, to establish a baseline of function, to monitor change over time, to plan useful intervention strategies, to advise family/carers and to determine the efficacy of treatment and intervention strategies.

A significant feature of dementia is the functional decline demonstrated by the increasing loss of ability to perform various daily living activities and later on this generally leads to the need for increased level of assistance and care. Being aware of the rate and impact of functional decline is helpful in planning for both the present and the future.

Historically, occupational therapists in dementia care have worked with people in the middle to late stages of the disease. Recent developments in medication have led to the need for an earlier diagnosis of dementia and it is suggested that referral to services at this early stage would enable people to learn coping strategies and would therefore enable people to function better for longer into their illness.

Physiotherapists

Physiotherapy input can contribute to encouraging and helping people with dementia and FMI to remain active and maximise their physical potential. Physical activity can promote better sleep, more regular bowel habits and has been shown to be effective in reducing the amount of agitated pacing a person with dementia may do. Access to physiotherapy services for musculo-skeletal, neurological problems, chest conditions etc. is as important for this service user group as for any other and it is important that such access is facilitated where necessary.

Speech and Language Therapists

Communication is of critical importance in the assessment and management of dementia. It is often the area which carers find most difficult to cope with as its breakdown affects relationships, causing distress for all concerned. Developing communication skills of professionals and carers can enhance the quality of life for the person with dementia. There is a need for increasing involvement of speech and language therapy in the assessment and management of older people with mental health problems, including dementia and related disorders, helping to maintain functional communication for as long as possible.

Dieticians

Dementia and FMI can often result in changes in a person’s eating habits and ability to eat. Dieticians can provide advice on issues such as poor appetite, weight loss or weight gain and food supplements.

Podiatrists

Healthy, pain free feet are important in maintaining mobility. Many older people will have significant pedal problems due to neglect, poor circulation, diabetes and access to a podiatry service is important.

Opticians

Problems with sight can add to confusion. Sight should be regularly checked by an optician who can examine the eyes for signs of glaucoma, cataracts and other eye and medical conditions.

Dentist

Regular dental care is essential to wellbeing and may be easily ignored in the older person with communication difficulties. It is important to ensure that teeth and gums are healthy and that dentures, where worn, are comfortable.

GLOSSARY

Acute Mental Health	Care provided within the hospital setting to Inpatient Care those individuals who require admission for purposes of assessment, treatment and/or rehabilitation
Care Pathways	Ensuring that patients with certain conditions have access to standardised basic forms of care and treatment
Continuum of care	The range of services and supports required to care for a person throughout the course of his or her illness
Dementia	A clinical syndrome characterised by a widespread loss of mental function which can result in memory loss, language impairment, disorientation and changes in personality and/or behaviour
Early Onset Dementia	People who develop dementia before they are 65 years of age
Functional Mental Illness (FMI)	A term used to refer to a number of mental health disorders, the most common of which is depression
Graduates	Those individuals who have suffered enduring severe mental disorder (or episodes of) in adulthood and who have reached the age of 65 and are transferring to older people’s services
Intermediate Care	Short-term care provided to either prevent admission to hospital or to facilitate early discharge. This care can be provided in a residential or nursing care context or within the person’s own home.
Interim Care	The provision of residential/nursing care to those individuals who present with challenging behaviour
Mainstream	Those services which are generally available to everyone in the community
Mental Health Issues	The “summary” term adopted by the Review to refer to both dementia and functional mental illness
Multi-disciplinary	A term used to refer to staff from different professions, e.g. nurses, social workers working together to plan and provide care and services to individual service users
Palliative Care	Those services offered to people with life-limiting illnesses

Primary/Community Care	Those health and social care services which act as the first point of contact and as a gateway to other services and which are generally provided within the context of the person's own home
Specialist Services	Services which are designed to meet the specific needs of a service user group. Such services are generally offered where there are complex levels of need

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Chapter 9
Workforce Planning Review DHSSPS (2006)

THE BAMFORD REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY
(NORTHERN IRELAND)

A COMPREHENSIVE LEGISLATIVE FRAMEWORK

August 2007

CONTENTS

ANNEXES

FOREWORD

The Bamford Review of Mental Health and Learning Disability (Northern Ireland) consists of a number of interlinked reviews under one overarching title, and comprises policy, services and legislation.

The Review's Steering Committee oversees the work of 10 major Expert Working Committees, 4 of which commenced their work by April 2003, with the remaining 6 by November 2003.

In consultation with Government, we have agreed to produce our reports separately in a phased manner, as the work has been completed. This is the final report from the Review and deals with the reform of law.

As with all of the other Expert Working Committees, the Legal Issues Committee has adopted an evidence-based approach to its work, drawing especially on recent developments in law and practice and taking account of the experience in the rest of the United Kingdom, in the Republic of Ireland and internationally on the introduction of mental health and related capacity legislation.

The Review is grateful to the many external contributors who have helped us develop our thinking on this important and complex subject; and I particularly want to thank Master Brian Hall who has chaired the Legal Issues Working Committee and has brought its work to this conclusion.

The Review's proposals for law reform are quite radical and must be given a high priority for implementation by Government.

I commend the Report to you.

Roy J McClelland (Professor)
Chairman

August 2007

PREFACE

The Minister for Health, Social Services and Public Safety established the Review under the Chairmanship of the late Professor David Bamford in October 2002. The Terms of Reference for the Review, set out in Annex 1, focused on the existing provisions of the Mental Health (Northern Ireland) Order (the 1986 Order) and directed that particular account be taken of issues relating to incapacity, human rights, discrimination and equality of opportunity.

The Legal Issues Working Committee (the Committee), together with its sub-groups, whose membership is set out in Annex 2, has examined all the provisions of the 1986 Order and has taken account of continuing developments in law and practice in neighbouring jurisdictions. The Committee has also taken careful account of the contributions of stakeholders and of the Reference Groups for users of services and for carers within the Review. These Groups have examined critically both the current level of service provision and the suitability of existing statutory powers to serve the needs of people with mental health difficulties or a learning disability.

This Report, therefore, represents the distillation of a great volume of work and the detailed consideration of particular topics scrutinised by the Committee's sub groups is available on the Review's website www.rmhldni.gov.uk

An easy-read summary version of this Report has been produced and is also posted on this website.

In addition, for ease of reference in reading this Report, a number of short terms or abbreviations have been used, a list of which appears in the Glossary.

ACKNOWLEDGEMENTS

The Review formally expresses its thanks to a number of experts in the field of Mental Health legislation from outside Northern Ireland and acknowledges the contribution they have made to the development of the proposals in this Report.

While frequent contacts and discussions have taken place with colleagues in Great Britain, the Republic of Ireland, Canada, New Zealand and the Netherlands, particular thanks are due (in alphabetical order) to:

• Professor Peter Bartlett	University of Nottingham
• Professor Phil Fennell	Cardiff Law School
• Professor Bill Fulford	Warwick University
• Professor Robert Gordon	Simon Frazer University, British Columbia, Canada
• Professor Michael Gunn	Nottingham Trent University (at that time)
• Master Denzil Lush	Court of Protection, London
• Dr Madeline Osborn and colleagues	The Mental Welfare Commission, Scotland
• Mrs Hilary Patrick	Mental Health Law in Practice, Edinburgh
• Mrs Patricia Ricard-Clarke	Law Reform Commission, Dublin
• Mr Tom Thomson	Public Guardian, Scotland
• Dr Tony Zigmond	Leeds Mental Health Trust

GLOSSARY OF TERMS AND ABBREVIATIONS USED IN THIS REPORT

ENACTMENTS

The 1983 Act	The Mental Health Act 1983
The 1986 Order	The Mental Health (Northern Ireland) Order 1986
The AWI Act 2000	The Adults with Incapacity (Scotland) Act 2000
The MHCT Act 2003	The Mental Health (Care and Treatment) (Scotland) Act 2003
The 2005 Act	The Mental Capacity Act 2005
The MH Bill 2006-2007	The Mental Health Bill 2006-2007

REPORTS

The Richardson Report	The Report of the Expert Committee: Review of the Mental Health Act 1983 (submitted in December 1999)
The Joint Committee Report	The Report of the Joint Committee on the draft Mental Health Bill 2004 (March 2005)
The Code of Practice	The Code of Practice issued by the Department of Constitutional Affairs (now the Ministry of Justice) setting out guidance on the 2005 Act
The MacLean Report	The Report of the Committee on Serious Violent and Sexual Offenders (submitted to the Scottish Executive, 2000)
The Millan Report	The Report on the Review of the Mental Health (Scotland) Act 1984, "New Directions" (laid before the Scottish Parliament in January 2001)

OTHER TERMS USED

The Review	The Bamford Review of Mental Health and Learning Disability (Northern Ireland)
The ECHR	The European Convention on Human Rights
The Tribunal	The Mental Health Review Tribunal for Northern Ireland
The Commission	The Mental Health Commission for Northern Ireland
The RQIA	The Regulation and Quality Improvement Authority
The Court	The High Court of Justice (Family Division)
The OLR	The Office of Law Reform – whose responsibilities have now been transferred to the Civil Law Reform Division of the Department of Finance and Personnel
User of services	A person who is receiving or may require health care services or treatment or who lacks capacity and who is receiving or may require protection or support under any statutory provision relating to the Review
Advocate	A person appointed to provide advocacy services (whether statutorily defined or otherwise)
Attorney	A person appointed by a user of services to act on behalf of him or her under a Lasting Power of Attorney
Nominated person	A person nominated to represent the interests of the user of services
RMO	Responsible Medical Officer

INTRODUCTION

1. The values base of the Review, as expressed in the Human Rights and Equality of Opportunity Report, has underpinned our consideration of legislative reform. We have sought to specify a comprehensive framework (hereafter referred to as the "Framework") for future legislation which reflects the need to respect the rights of all citizens, to provide rights for those whose freedoms may need to be interfered with on healthcare grounds, where appropriate, to protect public safety, and to encourage best practice generally.

2. The Framework proposals are not an attempt at legislative drafting, but a description and an explanation of what is considered necessary for reforming existing legislation, applying a principles-based approach.

3. The values base on which modern Mental Health legislation should rest (Chapter 1) and the need for changes to existing provision (Chapter 2) have been informed by a review of developments in human rights and Mental Health law (national and international) and by a review of the Mental Health (Northern Ireland) Order 1986 (Chapter 3). Detailed consideration has been given to the principles which should underpin future legislation (Chapter 4) and to how a principles-based approach should inform provision (Chapter 5). Based on these considerations, a new legislative Framework has been formulated (Chapter 6) and a model example presented to demonstrate how such a Framework might operate in practice (Chapter 7). The principal recommendations from this review of legislation and the next steps in this proposed reform process are then set out (Chapter 8).

4. A major advantage of the present Review has been the opportunity for a joined-up approach to service modernisation and reform of legislation. The legislative proposals within this Report will only be fully effective if there is a full range of appropriate community and hospital services. The specifics of such service provision are the subject of other Reports from the Bamford Review.

5. In the course of the Review, the Office of Law Reform (OLR) indicated its intention to bring forward proposals for Capacity legislation, in line with recent developments in Scotland, England and Wales. The proposal to introduce Capacity legislation for Northern Ireland is welcomed by the Review and OLR is awaiting the Review's proposals for legislative reform before proceeding further.

CHAPTER 1

VALUES AND PRINCIPLES

1.1 The comprehensive nature of the Bamford Review allows the same core values to run throughout its deliberations. This ensures an integrated and co-ordinated approach to its work.

1.2 The vision underpinning the Review is a valuing of those with mental health needs or a learning disability, including their rights to full citizenship, equality of opportunity and self determination. The vision also looks to a reform and modernisation of services that will make a real and meaningful difference to the lives of people with mental health needs or a learning disability, to their carers and families. It emphasises promoting the mental health of the whole community through preventative action. It acknowledges the essential role of carers and the importance of their own physical and mental well-being.

1.3 The Review has recognised from the outset that new legislative proposals for Northern Ireland should be based on agreed principles. They should have regard to human rights and the dignity of the individual and should provide equally for all circumstances in which an individual's autonomy might be compromised on health grounds.

1.4 Issues of compulsory detention raise a number of particularly difficult legal problems. The international and European evidence base, "suggests that a complex set of still poorly understood legal, political, economic, social, medical and multiple other factors seems to interact in the process of involuntary placement" (Faulkner, 1989). The local evidence base is limited. For these reasons, it is particularly important that the values and principles underlying any new legislation are clearly stated.

1.5 Our present concepts of human rights have developed from common law, the Universal Declaration of Human Rights in 1948 and the United Nations Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care in 1991. Principles reflecting these are increasingly being included in legislation as the basis of law where they can have even broader impact in shaping public attitudes and developing person-centred services, rather than separately specifying civil liberties and political freedom. This is in keeping with the European Convention on Human Rights and the spirit of the Human Rights Act 1998.

1.6 The commitment to a principled approach was promoted in the Review's Human Rights and Equality of Opportunity Report (2006) which states "Because a person has a mental health problem or a learning disability does not of itself mean that he or she is incapable of exercising his or her rights" (paragraph 4.5). That Report highlights (at paragraph 3.1) particular barriers preventing people from exercising their rights including:

- assumptions made about a person's capacity;
- lack of knowledge and/or support to exercise rights;

- unequal access to services and opportunities in employment, education, transport and access to and participation in the criminal justice system;
- stigma and prejudice; and
- staff attitudes.

1.7 The Report makes recommendations regarding:

- citizenship;
- involuntary detention;
- capacity;
- representation at Mental Health Review Tribunals; and
- advocacy.

These recommendations have informed the work of the Review and should be read in conjunction with this Report to provide the context of the principles described below.

The Principles Base

1.8 A sound ethical base for legislation is the cornerstone around which specific proposals should be formed. The following overarching principles, which are elaborated on in Chapter 5, recognise and support the dignity of the person. They form the basis of the Review's proposals for legislative reform:

i **Autonomy - respecting the person's capacity to decide and act on his own and his right not to be subject to restraint by others.**

ii **Justice - applying the law fairly and equally**

iii **Benefit – promoting the health, welfare and safety of the person, while having regard to the safety of others**

iv **Least Harm - acting in a way that minimises the likelihood of harm to the person.**

1.9 A principles base which respects the dignity of the person whose decision-making capacity is impaired will also respect the dignity and safety of others in the rare cases where that person's behaviour poses a risk. A balance must be struck between private rights and public safety.

1.10 While the principles necessarily refer to the individual concerned, those persons who provide informal care to users of services (such as family or friends) should be accorded due respect for their role and experience, be given appropriate and timely information and advice and have their views and their own needs taken into account.

1.11 Having a recognition and acceptance of principles does not provide a means of choosing between them. There remain fundamental tensions between autonomy and benefit, for example where emphasis on benefit can lead to paternalism. However the need to have regard to all the principles provides a balance in the process.

1.12 Principles underpinning legislation will only have effect if they are translated into clear provisions, if there are adequate services to provide good quality treatment and care to allow them to act as intended and when all those operating the legislation have adequate education and training. The impact of the principles in the Code of Practice for the 1986 Order was reduced because of delay in publication and a failure to deliver an associated training programme. Principles must be incorporated into the new law and elaborated upon in Codes of Practice. The new legislation, the Codes of Practice and related training programmes must be introduced at the same time.

CHAPTER 2

THE NEED FOR CHANGE

Legislation in Northern Ireland

2.1 The purposes of Mental Health legislation in Northern Ireland, as elsewhere, are:

- to provide the legal authority and basis for the delivery of mental health services;
- to protect people who are vulnerable by virtue of mental disorder or learning disability from abuse and exploitation; and
- to regulate the circumstances in which people with a mental disorder can be detained, and, if necessary, treated against their will, for their own protection and/or the protection of others.

2.2 Rooted in nineteenth century legislation that was primarily concerned with safety issues (public and private), the current law has moved towards a growing recognition of the rights of those most affected by the law – users of mental health and learning disability services.

2.3 Some of the major developments can be summarised by referring to the laws that made them possible, outlined below:

- The Mental Treatment Act (Northern Ireland) 1932;
- The Mental Health Act (Northern Ireland) 1948;
- The Mental Health Act (Northern Ireland) 1961; and
- The Mental Health (Northern Ireland) Order 1986.

2.4 Informal treatment for mental disorder became possible under the 1932 legislation and then became the norm after 1961. The 1961 Act also established a Mental Health Review Tribunal, which gave legal protection and a right of appeal to persons subject to compulsory detention and treatment.

2.5 A Mental Health Commission was introduced after 1986 to protect the individual's rights to care and treatment, and a revised power of Guardianship was created to protect and support patients in the community.

2.6 Legislation also made possible the establishment of new specialist services for people with learning disability and substance misuse (1948), the promotion of mental health (1961), the introduction of new approaches to assessment for hospitalisation, including special training for Approved Social Workers (1986) and, finally, a guaranteed right to information for users of services (1986).

2.7 The impetus for change at each of these stages of law reform came from changes in society and the professions, influenced by developments in other jurisdictions and by innovative practice at local level. Since 1986, new opinions have been articulated by health and welfare professionals (reflecting changes in scientific knowledge); by the public (reflecting changes in views on health, illness, safety, and risk); by lawyers (reflecting changes in mental health law elsewhere); and, most importantly, by users of mental health and learning disability services and their carers (reflecting their experiences with the current mental health system). The most important drivers of the current review can be summarised as follows:

- the voice of users of services and their carers;
- changes in society and professional practice;
- the Human Rights agenda;
- changes in Mental Health law in other jurisdictions; and
- the introduction of Capacity legislation in other jurisdictions.

Users of Mental Health Services and their Carers

2.8 Because of the importance of the opinion of those most affected by any change in Mental Health legislation, the perspective of this constituency is given priority here. On models of care, users of services and their carers told the Review:

- emphasis must be given to a holistic person-centred approach, which is respectful of the individual and delivered in a way that avoids stigma;

- services should be 'Recovery' focused, promoting a mutual connection between the clinician and service user, and involving a wide range of approaches to empower people to achieve their potential and lead a fulfilling life;

- advocacy services need to be developed (especially peer advocacy) as a valuable contribution to empowerment by assisting the individual to exercise choice in relation to care and treatment;

- responses to mental health crises need to be open, respectful and just, demonstrating accountability and transparency;

- policies and services need to be based on human rights, equality and assessment of need;

- community service responses should be the norm as there is still a fear of institutionalisation among users of services; and

- mental health services need to be adequately resourced.

2.9 In relation to possible changes in the law, users of services and their carers highlighted the following points:

- a welcome for the shift in focus towards a capacity-based approach;

- adequate legal protection must be in place for people subject to compulsory powers of any kind, whether in hospital or in the community;

- people with personality disorders should not be discriminated against, either directly or indirectly. They should have access to services which may be of benefit to them; and

- some users of services expressed concern about proposals to broaden the current criteria for compulsory admission to hospital by including psychological as well as physical harm as a risk.

2.10 Users of services have a significant contribution to make to staff education and training and to service planning and delivery.

2.11 Concerns about treatment approaches centre around the perceived emphasis on medication with insufficient choice in both the relative importance of medication and its type. The need for more therapies guided by psychological and social approaches was emphasised, echoing the holistic approach above.

2.12 Users of services recommend the introduction of Living Wills or Advance Directives for mental health treatment so that their views can be known and respected.

2.13 Carers acknowledge the complex and sensitive relationships issues that can arise with mental health services users and their families. Carers also emphasise the contribution they can and wish to make to the development of care plans and the delivery of appropriate support packages to users of services.

2.14 Carers seek respect for their role and an obligation for them to be consulted and involved in service planning and delivery.

Changes in Society and Professional Practice

2.15 There have been significant developments in community-based care. These have extended alternatives to hospital care and treatment and should result in more local options in less restrictive forms of care. These include Home-based Treatment and Assertive Outreach teams and the further development of social and psychological therapies, as described in the Review's Report, A Strategic Framework for Adult Mental Health Services (2005).

2.16 For people with learning disability, it is accepted that community living with appropriate support and care is the norm, with specialist treatment needs met using the same standards and, where possible, the same services as others (Equal Lives Report (2005)). There have been developments in diagnostic practice to improve the identification of mental illness affecting people with a learning disability (Diagnostic Criteria – Learning Disability (2001)) and, in turn, more appropriate treatment and services have been developed.

2.17 Issues of stigma continue to be identified. Despite advances in practice, the use of Mental

Health legislation in situations of care and treatment continues to be experienced as stigmatising to many individuals, including those with a learning disability.

2.18 The advocacy movement continues to grow and gain recognition. This has enabled more effective participation of users of services and their carers in the planning, delivery and monitoring of services.

2.19 There is a general acknowledgment among mental health professionals that social and environmental factors impact on mental health and illness. Therefore, in more complex cases, single solutions based on medicine alone need to be replaced by multi-disciplinary approaches to care that address the relevant biological, psychological and social factors.

Human Rights Requirements

2.20 Although the European Convention on Human Rights (the ECHR) had been in existence for decades and, with it, the European Court of Human Rights, a series of cases focusing on possible infringements of rights in the provision of mental health care led to an increasing concern about gaps in the existing statutory provisions throughout the United Kingdom. While some of these cases have focused on people who lack decision-making capacity, others have highlighted the rights of people with a psychiatric diagnosis (regardless of their legal status) to a full assessment of their situation, a fair hearing if they object to treatment, and to representation and advice in relation to decisions that will affect their lives and those of their children.

2.21 The passing of the Human Rights Act 1998 resulted in the incorporation of the ECHR into United Kingdom domestic law and highlighted the need for Mental Health law to be revised to ensure compliance with the ECHR. This reinforced the importance of individual rights and freedoms and made more explicit the duties and obligations of those who are responsible for implementing and monitoring legislation that impacts on vulnerable people.

2.22 The Northern Ireland Human Rights Commission, having considered the1986 Order in the light of the new human rights agenda, produced a report, Connecting Mental Health and Human Rights (NIHRC, 2003).

2.23 This report has served as a valuable source of comment to the Review, whose own Report, Human Rights and Equality of Opportunity, has confirmed the need for Mental Health legislation in Northern Ireland not only to take account of international concerns but also to comply with the equality obligations of Section 75 of the Northern Ireland Act 1998.

Changes in Mental Health Law in Other Jurisdictions

Scotland

2.24 In relation to the reform of Mental Health law, Scotland is ahead of other jurisdictions within the United Kingdom, with the Mental Health (Care and Treatment) (Scotland) Act 2003 (the MHCT Act 2003). The 2001 report, New Directions, of the committee established under the chairmanship of Rt. Hon. Bruce Millan to review the Mental Health (Scotland) Act 1984, formed the basis for this Act.

2.25 For the first time in the United Kingdom, Mental Health legislation begins with a statement of principles on which all interventions must be based. Informal treatment is regarded as the norm. The ethical and practical basis for compulsory detention and treatment was revisited by the committee and it was recommended that it should be the combination of impaired judgement, risk, and benefit to the individual with mental disorder.

2.26 There is a significant strengthening of the rights of users of services in the MHCT Act 2003, including new rights for voluntary patients; rights to assessment and to services (under the principle of reciprocity); the introduction of Advocacy support; and the encouragement of the use of Advance Statements for mental health care and treatment.

2.27 This legislation was implemented in October 2005 and its operation is being carefully monitored by the Scottish Mental Welfare Commission. Scotland also had the advantage of having a parallel process examining the assessment and risk management of high risk offenders through the MacLean Committee (Report of the Committee on Serious Violent and Sexual Offenders, Scottish Executive, 2000). Emphasis is on the risk posed rather than the cause of it and, since 2003, risk is managed in the same way for all such offenders, whether or not they have a mental disorder.

England and Wales

2.28 In England and Wales, the Department of Health established an Expert Committee under the chairmanship of Professor Genevra Richardson to review the Mental Health Act 1983 (Richardson Report, 1999). The Committee re-examined the ethical basis for the use of compulsion for people with a mental disorder and highlighted the pivotal importance of the effect of the mental disorder on the individual's decision-making, by suggesting that impaired decision-making be considered as the basis of interventions in Mental Health legislation. Although the Joint Committee of both Houses of Parliament set up to scrutinise the Mental Health Bill 2004 supported this view, the Government rejected this and other proposals and the Bill was subsequently withdrawn.

2.29 A decision was then made by the Government in November 2006 to amend the 1983 Act rather than introduce a comprehensive new statute. The main proposals in the MH Bill 2006-2007 are more limited in their modernising objectives. The Bill seeks to introduce supervised community treatment, to simplify the definitions and exclusions, change the treatability criterion for compulsory treatment and extend professional roles. While strengthening some patient protections and addressing Human Rights incompatibilities it does not include patients' rights to Advocacy services. Advance Statements about treatment may be included in the Code of Practice but not in the legislation. Principles should be set out in a Code of Practice but not on the face of the legislation.

The Republic of Ireland

2.30 In the Republic of Ireland, the most recent Mental Health law is the Mental Health Act 2001, significant elements of which were implemented on 1 November 2006. It is an easily read statute which strengthens the rights of users of service by introducing a Mental Health Commission and gives early automatic reviews of detention for every patient by a Mental Health Tribunal. Initiatives in relation to care of older people, vulnerable adults and individuals who lack capacity will also have an impact on mental health services. The land border between Northern Ireland and the Republic gives particular significance to this legal interface between these jurisdictions.

The Introduction of Capacity Legislation in Other Jurisdictions

2.31 Extensive debates took place in England and Wales throughout the 1990s on the need for legislation to underpin common law in situations where decisions have to be made for persons who lack the capacity to make those decisions themselves (often because of mental disorder or disability). These debates led to the Law Commission's Report on Mental Incapacity in 1995, the Green Paper "Who Decides? Making Decisions on behalf of Mentally Incapacitated Adults" in 1997 and Government proposals for legislation outlined in a White Paper "Making Decisions" in 1999.

2.32 It was clear that, with the exception of some provisions for the protection of the property and finances of certain individuals under existing Mental Health legislation, there were very few legal protections in these situations. The Human Rights Act 1998 highlighted the need for legal justification for any interference with the rights of another person and legal protection for those who do so.

2.33 Scotland was first to pass a statute to meet the concerns articulated by these debates - the Adults with Incapacity (Scotland) Act 2000 (the AWI Act 2000). This Act includes provisions for welfare Guardianship which originally fell under Mental Health legislation, while the Adult Support and Protection (Scotland) Act 2007 further strengthens protections for adults at risk of abuse. Significantly for the work of the Northern Ireland Review, the Millan Committee recommended that Mental Health law and Capacity provisions should, in due course, be consolidated into a single Act.

2.34 In England, the progress of the case commonly referred to as the Bournewood Case through the House of Lords to the European Court of Human Rights (HL v UK, 2004, see Annex 3) highlighted the lack of legal protections for compliant persons who are deprived of their liberty at a time when they lack the capacity to object.

2.35 The Government originally published a draft Mental Incapacity Bill for England and Wales which was examined in detail by a Joint Scrutiny Committee of both Houses of Parliament. Many suggestions made by that Committee led to the promotion of a revised Bill which, with further amendments made during its Parliamentary stages, was passed as the Mental Capacity Act 2005 (the 2005 Act).

2.36 The Irish Law Reform Commission in Dublin has recently published a report on Vulnerable Adults and the Law, setting out clear proposals for statutory provisions in relation to mental capacity and Guardianship. The report includes a Draft Scheme for a Bill to implement its key recommendations.

2.37 Northern Ireland stands alone within the United Kingdom in not having a statute dealing with Capacity. The OLR originally carried out a consultation exercise in Northern Ireland on the Lord Chancellor's Green Paper (1997) and began a preliminary examination of the Mental Capacity Bill 2004 during its Parliamentary stages in 2005. In acknowledgement of the emerging interface with other related legislation, however, the OLR is waiting for the conclusions of the Bamford Review before proceeding with this work.

2.38 The experience gained from the introduction of Capacity legislation in England and Wales and in Scotland and the proposals for law reform in the Republic of Ireland point to the importance of considering carefully the interface between the two types of legislation, Mental Health statutes and Capacity law, and provide valuable information for proposed legislation in Northern Ireland.

The Convention on the International Protection of Adults

2.39 The International Convention signed at The Hague on 13 January 2000 makes essential provision for the recognition and enforcement of protective measures made in respect of the person or property of an incapacitated adult in other Convention countries. The Convention has been ratified in Scotland by the AWI Act 2000 and in England and Wales by the 2005 Act. The implementation of the Convention in Northern Ireland would be welcome.

The Convention on the Rights of Persons with Disabilities

2.40 The General Assembly of the United Nations adopted a Convention on the Rights of Persons with Disabilities on 30 March 2007 and it has already been signed by a majority of member states, including the United Kingdom. The provisions of the Convention are designed to afford additional protections for all persons with disabilities, including children, and it should be ratified in Northern Ireland.

CHAPTER 3

AN APPRAISAL OF THE 1986 ORDER

3.1 In formulating proposals for changes in legislation it has been essential to make a careful appraisal of the 1986 Order, its strengths and weaknesses, against the background of significant changes in Mental Health and Capacity legislation introduced or proposed in neighbouring jurisdictions. Account has been taken of the submissions made to the Review by users of services, carers and other stakeholders. The Committee and its sub groups have also had the benefit of considering the detailed analyses contained in the reports of committees and other commentaries relating to recent developments in Scotland, England and Wales, and in the Republic of Ireland.

General Comments

3.2 The 1986 Order incorporated many of the recommendations contained in the Report of the Northern Ireland Review Committee on Mental Health Legislation (October 1981) (the MacDermott Report) and also took account of the provisions then enacted in the English 1983 Act and the Mental Health (Scotland) Act 1984 – both of which had been subjected to detailed scrutiny and amendment during their passage through Parliament. The overall purpose of the Order was to provide for care, treatment and protection of people suffering from mental disorder. The measure is a combination of powers and protections including compulsory hospital-based detention and treatment, involuntary community care without treatment provisions (Part II), provision for those involved in criminal proceedings (Part III), separate consideration of capacity to consent to treatment for mental disorder (Part IV), protections for all those with mental disorder through the Mental Health Commission (the Commission) (Part VI), legal protections for those detained through the Mental Health Review Tribunal (the Tribunal) (Part V), "capacity type" protections for people with mental disorder who are unable to manage their financial affairs (Part VIII), and protections from sexual and other abuse through defining specific offences (Part X).

3.3 Significant features of the Order have been the provision of Guardianship as a less restrictive alternative to detention in hospital, establishment of a Mental Health Commission, increased access to the Mental Health Review Tribunal, more stringent criteria for compulsory admission to hospital, an assessment period before detention for treatment, consent to treatment provisions and arrangements to keep patients and their nearest relatives fully informed of their rights. The Order also provided for management and administration of the financial affairs and property of people deemed incapable by reason of mental disorder. To ensure the proper implementation of the legislation a Code of Practice was to be introduced and revised from time to time and, in recognition of the importance of social factors and circumstances, a duty was imposed on Health and Social Services Trusts to appoint adequate numbers of competent Approved Social Workers.

3.4 However, the use of compulsory powers was based on "substantial likelihood of serious physical harm", with narrower criteria than anywhere else in the United Kingdom, thereby excluding some people with severely deteriorating conditions by disregarding psychological harm. The specific exclusion of persons disabled "by reason only of personality disorder" may have disadvantaged such persons in accessing assessment and treatment.

3.5 The Code of Practice was not issued until five years after the Order came into operation and the introduction of the Order was not supported by a comprehensive education or awareness strategy. The Commission was not adequately resourced and as a consequence it could not satisfactorily fulfill its function to monitor and protect those outside hospital. Experience of the use of the Order has shown difficulties with the application of terms used - for example, "severe mental impairment". There are many aspects of its operation which users of services and carers find paternalistic.

3.6 A range of submissions from stakeholders also highlighted widespread concerns about the absence of a statutory basis for decision-making on behalf of adults, the need for services to be adequately resourced to allow informal access to care and treatment where possible, the limited usefulness of the powers of Guardianship and the role of a nearest relative as applicant for compulsory admission.

Compulsory Admission to Hospital

3.7 Part II of the 1986 Order, reflecting equivalent provisions in the English 1983 Act and giving effect to key recommendations in the MacDermott Report, sets out the procedures relating to the compulsory admission of patients to hospital – initially for assessment and, if necessary, for treatment. The principle of having a period of assessment with broader entry criteria has worked well and may serve as the basis for future practice subject to essential amendments. However, there is a need for re-definition of the grounds upon which an application for assessment should be founded and of the essential roles to be discharged by professionals involved.

Admission Procedures

3.8 The Review's Report on Human Rights and Equality of Opportunity (2006), identified a concern about the second ground upon which an application must be founded (in Article 4(2)(b)) that "there is a substantial likelihood of serious physical harm to himself or to other persons" and it is noted that in the MHCT Act 2003 in Scotland this statutory requirement has been expressed as "a significant risk to the health, safety or welfare of the patient or to the safety of any other person."

3.9 It is the general view that the special status accorded to the nearest relative of a patient in the 1986 Order and, in particular, the right of that person to make an application for assessment, defined in Article 5(1)(a), should be repealed. On the other hand, it is essential that full recognition be given to relevant views expressed by attorneys, nominated persons, carers and, where appropriate, the nearest relative. If no such representative of the patient is available to be consulted and informed of proposals to have the patient admitted to hospital for assessment and treatment it should be essential to engage the service of an independent (accredited) advocate.

3.10 The current requirements of Article 4(3) of the Order envisage that the medical recommendation required in support of an application may be supplied by the patient's own GP or another doctor who has recently been involved in his/her care or treatment. Following the introduction of the General Medical Service contract it has become increasingly difficult to ensure that the first choice sources of supporting recommendations should be knowledgeable and experienced practitioners – as contemplated in the general provisions prescribed in Article 6 of the Order. In practice it has been increasingly apparent that recommendations are being sought from another doctor in general practice or a doctor in hospital who may have limited knowledge of the statutory procedures or diagnostic issues involved and no previous connection with the patient. There is an incontrovertible case for insisting that all professionally qualified persons engaged in the initial stages of an application should be trained and approved for the purpose. Appropriate facilities should be provided to enable such sensitive and stressful interventions to be undertaken with dignity and in privacy.

3.11 While the preliminary recommendation for admission and the initial confirmatory assessment made by the hospital doctor formally admitting the patient may be undertaken by professionals trained and accredited for those purposes, a more detailed assessment must be undertaken by a responsible medical officer of consultant status, as soon as possible. It will be essential to review the present arrangements for the appointment of appropriate practitioners for the purposes of Part II by the Mental Health Commission so that accredited training is a pre-requisite. It is also been submitted that in order to make a satisfactory comprehensive assessment in complex cases the periods permitted by Article 9(7) and (8) – up to 14 days, is not sufficient and should be extended with appropriate protections.

Guardianship

3.12 Guardianship, as now defined in Articles 18-26 of the 1986 Order, is intended to provide a means of caring for certain mentally disordered people who require formal supervision in the interests of their welfare but who do not need to be detained in hospital. The care provided may relate to more effective protection of their welfare or living arrangements, require the person to attend for medical treatment, occupation, education or training and to allow access to specified professionals.

3.13 Guardianship has been used successfully to protect persons with severe mental handicap and increasingly with persons with dementia and with chronic mental illness. The optimum benefit of Guardianship can only be achieved by the willingness of all the parties involved to work together and concerns have arisen regarding lack of clarity around issues of compulsion, for example to return the person to the designated residence. There is, in addition, a need to clarify the procedures which may lead to emergency applications for the protection of a patient and to ensure that short term welfare arrangements are accessible immediately.

Patients Concerned in Criminal Proceedings or Under Sentence

3.14 Part III of the Order contains provisions for patients concerned in criminal proceedings or under sentence. These include powers that enable Courts to remand an accused person to hospital for a report on his mental condition (Article 42), to remand a person to hospital for treatment (Article 43), to make a person the subject of a hospital order or guardianship order (Article 44) or an interim hospital order (Article 45). Part III of the Order also contains provisions for transfer direction orders which enable the transfer of prisoners to hospital for treatment and it contains arrangements in relation to individuals who are found legally insane or unfit to stand trial. In certain situations, where it is necessary to protect the public from serious harm, individuals may be made the subject of a restriction order which restricts their leave, transfer or discharge from hospital.

3.15 Thus the Order contains many useful provisions that form a solid legislative foundation for the assessment, treatment and care of mentally disordered offenders and others with similar needs. The Review's Report on Forensic Services (2006) has made wide-ranging recommendations for the future development of forensic services. In order to support these proposals and to update the current legislation a number of issues require to be addressed, for example:

- The powers to remand individuals to hospital do not extend to the Court of Appeal and do not make provision for the granting of temporary leave in appropriate circumstances;

- When recommendations are made to the Court for disposals such as a hospital order there are no specified time periods within which the individual should have been assessed;

- Where there are recommendations to the Court that an individual should be admitted to hospital but the individual is acquitted at Court there are no arrangements to provide for appropriate assessment, treatment and care;

- There are no legal mechanisms to ensure that certain types of prisoners, such as those on remand or those who may require an interim hospital order, can be transferred to conditions of high security for assessment, treatment and care;

- Prisoners who are transferred to hospital for treatment under the current Mental Health legislation are treated on a compulsory basis even when they have the capacity to accept their treatment on a voluntary basis;

- Prisoners can be transferred to hospital for treatment while the subject of a transfer direction order, but the current arrangements do not provide for transfer for assessment followed by treatment;

- The current arrangements could be improved to ensure that the Court makes its decisions on disposal after the individual has undergone detailed assessment;

- The range of disposal options for mentally disordered offenders could be increased in line with experience in other jurisdictions;

- Additional rights of appeal should be introduced in certain circumstances, including a right of appeal against detention in conditions of excessive security or restriction;
- Outmoded or pejorative terminology should be replaced, for example in relation to the legal term "insanity"; and
- Measures under the Mental Health legislation which aim to protect the public from serious harm should be placed within a wider risk management framework so that they do not discriminate unjustifiably against people suffering from certain types of mental disorder.

Consent to Treatment

3.16 Part IV of the 1986 Order introduced new statutory provisions to clarify the circumstances in which detained patients (including patients admitted for assessment) may be given specified treatments for mental disorder without their consent and extended protections to all patients for some of the most serious treatments.

3.17 Services users' and carers' representatives have also been concerned to ensure that full protection will be afforded to a patient in establishing his/her known wishes in relation to particular forms of treatment.

3.18 Particular concern was expressed about the provision to allow the use of electro-convulsive therapy (ECT) for those who retain decision-making capacity and also the extent to which advance decisions indicating the refusal of certain treatments might be ignored by doctors proposing particular treatments.

3.19 There is a need to revisit the circumstances in which decisions might be made about treatment on behalf of other people and to revise the classification of specified treatments taking account of the re-appraisal of such treatments in England and Wales and the new definition of treatments and additional safeguards found in the MHCT 2003 Act in Scotland.

The Mental Health Review Tribunal for Northern Ireland

3.20 The Tribunal was established in Northern Ireland by the 1961 Act to provide a safeguard for detained patients specifically against unjustified detention by means of a review of the detention from medical, legal and lay points of view. Part V of the 1986 Order sought to strengthen the Tribunal (by increasing its membership and widening its powers) and also extended the rights of access to it. The patient is prima facie entitled to be at liberty and the burden of proof is on the detaining Authority as clarified by the Mental Health (Amendment) (Northern Ireland) Order 2004 to ensure compliance with the Human Rights Act.

3.21 Stakeholders generally support the existence of a Tribunal system. However, the following concerns have been expressed by users of services: a patient is often regraded to voluntary status just before a Tribunal hearing, which leads to lack of accountability for the preceding period of detention; the choice of venue where hearings are held may not be appropriate; for a variety of reasons patients are often unwilling to ask for Tribunal hearings; and patients would welcome the support of skilled advocacy services.

3.22 Professionals expressed concern about adequate hearings for those patients who refuse legal representation and about the potential detrimental effect of a full hearing against the patient's wishes in those cases referred for automatic review. The Review's Human Rights and Equality of Opportunity Report makes specific recommendations in relation to the entitlement of patients to have specialist legal representation before the Tribunal without charge; to appoint a representative of his/her choice; and to have the assistance of an advocate, when appropriate.

The Mental Health Commission for Northern Ireland

3.23 Part VI of the 1986 Order established the Commission as an independent multi-disciplinary body with regulatory, investigative, inspectorial and advisory functions. The primary function of the Commission, defined in Article 86(1), is to "to keep under review the care and treatment of patients", to protect the interests of mentally disordered individuals and to safeguard staff involved in their care and treatment. For this purpose such individuals may be patients – both voluntary and detained, persons placed in Guardianship, persons receiving out-patient care and those residing in nursing or residential care accommodation (and anyone else suffering from mental disorder). The discharge of that wide-ranging responsibility has been constrained from the outset by the lack of resources and the lack of an agreed operational plan.

3.24 Since the start of the Bamford Review there has been a fundamental Review of Public Administration throughout Northern Ireland. As part of that initiative the Secretary of State made a formal announcement on 21 March 2006 of his intention to proceed with a transfer of the functions of the Commission to the Regulation and Quality Improvement Authority (the RQIA) to be achieved by April 2008.

3.25 It will be essential to establish a comprehensive range of functions to be defined in new legislation – supplementing the present range of responsibilities of the RQIA set out in the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003. The RQIA should monitor and regulate the services provided to people with mental disorder or learning disability irrespective of where they may receive care or treatment – in the community, in hospital or in prison. The new arrangements must guarantee the delivery of an effective service replacing and extending the role of the present Commission.

Management of Property and Affairs of Patients

3.26 The provisions set out in Part VIII of the 1986 Order, based upon the equivalent sections of the English 1983 Act, define the circumstances in which the Court may exercise jurisdiction in relation to the property and affairs of a person who lacks capacity to manage such matters as a result of mental disorder. The current arrangements must therefore be reviewed in the light of the 2005 Act. It will be necessary to consider the replacement of the present provisions of Part VIII in conjunction with recommendations which cover the enlargement of the jurisdiction of the Court and related procedures including the creation of Lasting Powers of Attorney which should be introduced in Northern Ireland.

The Court

3.27 All jurisdiction relating to persons with impaired decision-making capacity in Northern Ireland is vested in the High Court and judicial responsibility lies with the Family Judge (or another Judge assigned by the Lord Chief Justice) and with the Master (Care and Protection). In this respect the position in Northern Ireland differs from that in England and Wales where the Court of Protection is established outside the High Court. The Review does not consider that the creation of a separate Court of Protection would be necessary or appropriate for Northern Ireland and there is adequate provision in the Judicature (Northern Ireland) Act 1978, as amended, to assign responsibility to Judges and statutory officers and to deal with the arrangement of Court business at specified venues.

The Office of Care and Protection

3.28 The current responsibilities of the Office of Care and Protection (the OCP), which is a department of the High Court, will have to be critically re-examined in the light of new arrangements for the discharge of equivalent functions in Scotland and in England and Wales. The creation of a separate statutory office of the Public Guardian has recently been recommended by the Law Reform Commission in the Republic of Ireland. The specific management and supervisory role of the post of Public Guardian in each of these jurisdictions is seen to be quite distinct and separate from the judicial functions of the Court.

3.29 The range of functions currently undertaken in the OCP is significantly greater (and arguably more effective) than is found in neighbouring jurisdictions. The availability of legal services to assist the OCP has been an essential component in the present system – providing valuable guidance in the initial stages of a case.

3.30 Having regard to the developing trends in neighbouring jurisdictions to restrict, as far as possible, official involvement in the financial affairs and welfare needs of an individual it will be necessary, in particular, to distinguish between office functions relating to formal applications to the Court and the current investigative and case management roles of the OCP considered in the next paragraph. The latter (purely executive) tasks should be critically reviewed and specific responsibilities re-assigned.

The Duty to Notify the Office

3.31 It is apparent from the terms of the 2005 Act and the Code of Practice in England that an application to the Court is intended to serve as a remedy of last resort and, so far as possible, the affairs of an incapacitated adult should be resolved without recourse to formal legal proceedings. In contrast, the 1986 Order imposes on local Health and Social Services Trusts a statutory duty (which is unique to Northern Ireland) to notify the OCP of cases where any of the powers of the Court ought to be exercised. While these arrangements have worked well and have provided a valuable level of protection to individuals and to social work staff, there is a need to define more precisely the circumstances in which formal intervention (or "whistle blowing") would be justified in future.

3.32 If it is assumed that responsibility to make provision for an adult's welfare arrangements and personal needs should, in the first instance, lie with the person himself, his family, carers or nominated persons, the involvement of any outside agency should only arise where there is apparent neglect or risk to the adult. The local system of "early warning" of difficulties involving an adult has hitherto provided a higher level of protection than is found in other jurisdictions.

Offences

3.33 There is a need to review the range of offences and penalties now prescribed in Part X of the 1986 Order. The majority of those offences and of other new offences relating to incapacitated adults in the AWI Act 2000 and in the 2005 Act should be included in new legislation resulting from the Review. The two remaining offences defined in Article 122 (Protection of women) and Article 123 (Protection of patients) are being considered in the current review of the law relating to sex offences in Northern Ireland, which will extend the protections offered to vulnerable persons, as in England and Wales.

Places of Safety

3.34 Concerns have been expressed about the inclusion of a police station in the list of premises or establishments, other than a hospital, defined in Article 129(7), to which a patient may initially be removed by a constable as a place of safety. While it may be that the present definition should be preserved, the Department of Health, Social Services and Public Safety (DHSSPS) should undertake to provide a list of other suitable places at which patients may properly be detained and to which they may be delivered by a police officer exercising new powers for the removal and detention of persons believed to be suffering from mental disorder.

Patients removed to or from Northern Ireland

3.35 Article 134 of the 1986 Order provides for the mental disorder of patients to be reclassified following their transfer from Great Britain and also provides for notification to be given in advance of a proposed transfer of a patient to Great Britain. Difficulties have arisen in practice by reason of the different between sub-categories of mental disorder and the exclusions set out in Article 3 of the Order and the corresponding statutory provisions in other parts of the United Kingdom.

3.36 It is essential that new legislation should authorise the issue of regulations dealing with the transfer of patients subject to corresponding measures enacted in adjoining jurisdictions.

The lack of effective transfer arrangements with the Republic of Ireland is of special significance in view of the need to provide secure care and treatment for detained patients in the most appropriate part of Ireland.

CHAPTER 4

THE IMPORTANCE OF PRINCIPLES FOR LEGISLATION

Principles and the Mental Health (Northern Ireland) Order 1986

4.1 The work of the current Review relating to the mental health provisions in the 1986 Order has coincided with preparatory work by the Office for Law Reform (see paragraph 2.37) to introduce new Capacity legislation in Northern Ireland. This has provided a unique opportunity to consider the overall purpose of legislation, the guiding principles underpinning legislative reform and an opportunity to develop a comprehensive approach to protecting and respecting the dignity of people with mental health problems.

4.2 While some elements of the current legislation are considered to work well (Chapter 3), it has become clear that aspects of the 1986 Order may not be human rights compliant. Neither is it in keeping with developments in good practice, which emphasise partnership between patients and professionals and a holistic approach to care and treatment. Nor is it based on the principles which the Review has identified as essential. The individual's autonomy may be over-ridden in the interests of his own or other's safety, and the legal powers focus on compulsion, rather than ensuring appropriate treatment.

4.3 There is, moreover, no provision under the current Mental Health legislation to offer protections for patients who are incapable of consenting to admission or treatment, with the exception of particular treatments in Part IV, as long as they are not resisting and are not posing a significant risk to themselves or others (The "Bournewood Gap", see Annex 3)

4.4 The Review considered the implications of including some of those provisions currently in the 1986 Order (for example finance, Guardianship and aspects of consent to treatment) within the proposed Capacity legislation. There was a reluctance to recommend that Guardianship be dealt with in a Capacity statute without retaining proportionate protections for the restrictions involved, which are currently not included in Capacity legislation. Much of the difficulty arises because the fundamental assumptions in the statutes are different. The need to have consistency across all the areas of provision in terms of underlying principles and definitions was seen as crucial

4.5 A principled, human rights-based approach moves from public protection as the priority towards safeguarding the rights and dignity of people with mental disorder and ensuring their access to appropriate care and treatment. When these have been firmly established for issues affecting the individual, it will then be necessary in some cases to balance these individual rights with the rights of others who may be placed at risk through the individual's behaviour. Adequate and proportionate protection must be ensured within legislation.

4.6 Mental Health legislation considered from a principles base requires a comprehensive approach which recognises the overlap with capacity issues, the needs of children and of those within the Criminal Justice System, including the interfaces with relevant legislation.

Requirements of Future Legislation

4.7 A rights-based approach is proposed as the guiding principle for reform of legislation, which should respect the decisions of all who are assumed to have capacity to make their own decisions. Grounds for interfering with a person's autonomy should be based primarily on impaired decision-making capacity. New legislative solutions are, therefore, required for issues posed by the effects of disorder of the brain or mind on an individual's decision-making capacity and which affect his/her own personal health, the need for care and treatment, safety and the welfare or the safety of others.

4.8 Legislative solutions must:

- respect and balance the key principles proposed by the Review (in Chapter 1), Autonomy, Justice, Benefit and Least Harm;
- reduce discrimination and stigma;
- be acceptable to and acknowledge the needs of users of services and their carers;
- acknowledge the need for provision of risk management and protection of self and the public, but maintain a healthcare focus;
- consider the need for "risk of serious harm" based legislation to override autonomy in those who retain capacity and find the best legislative place for this if required;
- use congruent principles, definitions and provisions to acknowledge the common population affected by Capacity and Mental Health legislation, and leave no gaps or confusion;
- acknowledge and make provision for variations in decision-making capacity over time in those affected by mental disorder, and balance these with benefit;
- clarify the interface with other legislation, for example, Criminal Justice and Children's legislation;
- be clear and efficient for professional staff to operate;
- be adequately resourced; and
- translate the intentions of, and be compatible with, the ECHR.

4.9 The Review proposes that the provision of care and treatment for mental disorder in relation to offenders or suspected offenders, and also their protection from abuse or exploitation, should be dealt with under the same legislation as that which applies to non-offenders.

International Perspective on Legislation

4.10 There is no blueprint for this type of legislation and each jurisdiction has had to find the best solution for its own needs, culture, politics and time. However, the Review has benefited greatly from experience both internationally and elsewhere in the United Kingdom through literature reviews and contact with international and national experts. Particularly useful in this regard have been the World Health Organisation Resource Book on Mental Health, Human Rights and Legislation (WHO, 2005) and the two Reviews of Literature Relating to Mental Health Legislation commissioned by the Scottish Executive in 2001 and 2005.

4.11 The WHO Resource Book provides an international perspective on Mental Health legislation and highlights the key issues and principles that need to be incorporated into legislation for the policies and plans it implements to meet internationally accepted standards and good practice. It examines different models of achieving the best legal solution which might be tailored to each jurisdiction, emphasising the need for realistic and attainable goals within local constraints.

4.12 Progressive legislation can be an effective tool in promoting access to mental health care as well as promoting and protecting the rights of people with mental disorders. In the past, legislation has been perceived to focus on public protection and consequently may have been unnecessarily punitive and stigmatising to the individual. A principles-based legislation, to which the Review is committed, takes the different starting point of the individual's right to respect and dignity.

4.13 Legislation can also hinder policy development, for example, through not including provisions to support community treatment or through lack of enforcement powers. It works best if it is not regarded as an event but as an ongoing process that evolves with time. This necessarily means that legislation is reviewed, revised and amended in the light of advances in care and treatment and improvements in service development and delivery. Provisions should be made in the legislation for the establishment of regulations for particular actions that are likely to need more frequent modifications. Then these can be reviewed within the process laid down and allow a flexibility and responsiveness to be built in.

4.14 The breadth of what is included under the umbrella of Mental Health legislation extends from the narrow functions of compulsory interventions for the care and treatment of people with mental illness, to the broader function of establishing an entitlement to services and rights and protections for all persons who fall under the wider term mental disorder, and then further to include the consequences of mental disorder on decision-making with protections for their health, welfare and finances. This latter group overlaps with people who have impaired decision-making from other causes (Capacity legislation).

4.15 Different countries have developed very different models (WHO, 2005). In some countries there is no separate Mental Health legislation and provisions relating to mental health are inserted into other relevant legislation. Other countries have consolidated Mental Health legislation where all issues, including mental capacity, are incorporated into a single Act. Many countries have combined these approaches as the need for different aspects of legislation has evolved over time. A principles-based approach is not bound to follow any one model, but demands that the approach be comprehensive so that the same principles can apply throughout.

4.16 In England and Wales and in Scotland the current approach is to move from consolidated Mental Health legislation which incorporates very limited capacity-type provisions for financial decisions (as currently in Northern Ireland) to separate Mental Health and Capacity legislation. However, the Millan Committee in Scotland viewed this as a developmental stage and recommended consolidation of the legislation in due course. For future development of legislation in Northern Ireland, it is important to re-examine the purposes of these laws and how they fit the changing requirements of society and the approach the Review has adopted.

Origins of Mental Health Legislation

4.17 Mental Health legislation comes from a civil commitment and public protection background, where the emphasis originally was on detention for compulsory treatment based on the presence of mental disorder of a nature or degree to merit hospital based treatment, regardless of the capacity to consent, but dependent on the risk to self or others. In this model, a psychiatrist is usually given responsibility for decision-making and powers of removal and detention are given to other staff. Only treatments for mental disorder are authorised. These powers are closely monitored, reviewed and subject to appeal. They are expected to apply to only a few people who meet the strict criteria.

Origins of Capacity Legislation

4.18 In contrast, capacity-based schemes are a more recent legal development centred around authorising decision-making. They originally developed to provide for the management of property and finances of persons with deteriorating or enduring problems of brain or mind such as dementia or learning disability. Recent conceptual developments have moved from a status test, where a diagnosis brings with it a presumption of lack of capacity which is seen as enduring, to the use of a functional test where there is a presumption of capacity and each decision is considered separately.

4.19 If the person is found, following assessment, not to have capacity for the decision in question then substitute decision-making is authorised, either informally for others to act, or by an authorised decision-maker such as a Guardian or Deputy. Decisions must be made in the person's best interests and significant or disputed decisions are made by a Court. Increasingly, weight is given to advance statements of preference or refusals which the person may make while capacity is retained, or through authorising another person through lasting powers of attorney to make decisions on his behalf. Protections are largely substantive, through the process itself, rather than procedural, through a system of appeals.

The United Kingdom Position on Mental Health and Mental Capacity Legislation

4.20 As the Review considers that all persons with mental disorder should be respected and treated in the same ways, it was important to examine recent United Kingdom developments from these two standpoints, and in particular to consider those statutes which have adopted a principles base so that lessons can be learned from that experience.

4.21 In England and Wales, the Mental Health Act 1983 is essentially a civil commitment scheme that is now in the process of being amended through the MH Bill 2006-2007. The Government has resisted proposals to include principles in the amended Act. However, it will interface with the Mental Capacity Act 2005, which is a principles-based statute.

4.22 In Scotland, the Mental Health Care and Treatment Act 2003 comes from a civil commitment background and regulates compulsory treatment for mental disorder, as defined. It also promotes the rights to services and treatment of people with mental disorder and is principles-based. It straddles the two traditions in legislation by having both a status test (mental disorder) and a functional test (impaired decision-making) as necessary together with risk for compulsory interventions. It interfaces with the Adults with Incapacity Act 2000, which also is principles-based.

4.23 For developments in Mental Capacity legislation, the Review has considered both the 2005 Act in England and Wales and the AWI Act 2000 in Scotland. This Report focuses on the 2005 Act for a study of Capacity legislation, since it is widely acknowledged that it develops aspects of the Scottish model and, even more importantly, the OLR proposed its use as the starting point for a model for legislation in Northern Ireland.

4.24 Given the different traditions and assumptions outlined above about Capacity provisions (previously mainly applying to patients incapable of managing their financial affairs), many people primarily concerned with mental health treatment will not be familiar with important developments in this field which have implications for future practice regarding health and welfare, for some people with mental health and learning disability issues. While some of the structures and processes in England and Wales are different and legislation would have to be adapted to transfer to Northern Ireland, it is important to become familiar with the main proposals which may transfer.

4.25 There follows an outline of this very recent legislation which the Review has taken into account even though the significance of some of these changes is only emerging. More detailed consideration is then given to the principles-based Mental Health legislation in Scotland and the interface issues between these types of legislation.

Introduction to the Mental Capacity Act 2005

4.26 The 2005 Act in England and Wales aims to protect the interests of adults who lack the ability to make decisions about their own finances, welfare or health, including medical treatment, or who are unable to communicate their decision, because of an impairment of, or a disturbance in the functioning of, the mind or brain. It is based on a functional approach to decision-making: that is, each decision is separately considered. Its application includes decisions about treatment for people with conditions from which they may recover, including mental illness.

4.27 The Act enshrines in statute current best practice and common law principles concerning people who lack mental capacity and those who take decisions on their behalf. The Review welcomes many key aspects of the legislation, in particular that the principles are defined at the beginning of the Act. These are:

- a presumption of capacity - every adult has the right to make his own decisions and must be assumed to have capacity unless it is proved otherwise;
- the right for individuals to be supported to make their own decisions - people must be given all appropriate help before anyone concludes that they cannot make their own decisions;
- that individuals must retain the right to make what might be seen as eccentric or unwise decisions;
- best interests - anything done for or on behalf of people without capacity must be in their best interests; and
- least restrictive intervention – anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms.

4.28 These principles are, of course, very similar to the principles developed by this Review for inclusion in new legislation.

4.29 ***Assessing lack of capacity.*** The 2005 Act sets out a single clear test for assessing whether a person lacks capacity to make a particular decision at a particular time. It is a "decision-specific" test. No one can be labelled 'incapable' as a result of a particular medical condition or diagnosis. Section 2 of the Act makes it clear that a lack of capacity cannot be established merely by reference to a person's age, appearance, or any condition or aspect of a person's behaviour which might lead others to make unjustified assumptions about capacity.

4.30 ***The capacity test.*** This includes the ability to understand, retain, use or weigh the information as part of the process of making the decision, or communicate the decision. This definition allows for the influence of delusions or disorder of mood as described in the Code of Practice.

4.31 ***Best interests.*** Everything that is done for or on behalf of a person who lacks capacity must be in that person's best interests. The Act provides a checklist of factors that decision-makers must work through in deciding what is in a person's best interests. A person can put his/her wishes and feelings into a written statement if he so wishes, which the professional making the determination must consider. Carers and family members gain a right to be consulted

4.32 ***Acts in connection with care or treatment.*** The Act aims to protect without excessive bureaucracy. Section 5 clarifies that, where a person is providing care or treatment for someone who lacks capacity, then the person can provide the care without incurring legal liability. The key will be proper assessment of capacity and best interests. This will cover actions that would otherwise result in a civil wrong or crime if someone has to interfere with the person's body or property in the ordinary course of caring or treatment, for example, by giving an injection or by using the person's money to buy items for them.

4.33 ***Restraint/deprivation of liberty.*** Section 6 of the Act defines restraint as the use or threat of force where an incapacitated person resists, and any restriction of liberty or movement whether or not the person resists. Restraint is only permitted if the person using it reasonably believes it is necessary to prevent harm to the incapacitated person, and if the restraint used is proportionate to the likelihood and seriousness of the harm.

4.34 The Act deals with two situations where a designated decision-maker can act on behalf of someone who lacks capacity:

- ***Attorney*** *(appointed under LPAs)* - The Act creates a new form of power of attorney, a Lasting Power of Attorney (LPA) to replace the present Enduring Powers of Attorney (EPA). Under a LPA donors may appoint other persons to act on their behalf if they should lose capacity in future. In addition to dealing with property and financial affairs an attorney, acting under a LPA, may make decisions concerning the donor's personal welfare, including healthcare and consent to treatment; or

- ***Court appointed deputy*** - Deputies may make decisions on welfare, healthcare and financial matters as authorised by the Court, but will not be able to refuse consent to life-sustaining treatment. Where possible, the Court will seek to resolve an issue affecting a person who lacks capacity by making a declaration (as to whether a particular act is lawful) or a single order to provide formal authority for a specific purpose.

4.35 The Act aims to support the person's own autonomy and establishes a right to engage an Independent Mental Capacity Advocate (IMCA). An IMCA is someone appointed to support a person who lacks capacity but has no one to speak for them. The IMCA makes representations about the person's wishes, feelings, beliefs and values, at the same time as bringing to the attention of the decision-maker all factors that are relevant to the decision. The IMCA can challenge the decision-maker on behalf of the person lacking capacity if necessary.

4.36 ***Advance decisions to refuse treatment.*** Statutory rules with clear safeguards confirm that people may make a decision in advance to refuse treatment if they should lose capacity in the future. It is made clear in the Act that an advance decision will have no application to any treatment which a doctor considers necessary to sustain life unless strict formalities have been complied with. These formalities are that the decision must be in writing, signed and witnessed. In addition, there must be an express statement that the decision stands "even if life is at risk".

4.37 ***Research.*** The Act sets out clear parameters for research involving, or in relation to, a person lacking capacity may be lawfully carried out if an "appropriate body" (normally a Research Ethics Committee) agrees that the research is safe, relates to the person's condition and cannot be done as effectively using people who have mental capacity. The research must produce a benefit to the person that outweighs any risk or burden. Alternatively, if it is to derive new scientific knowledge it must be of minimal risk to the person and be carried out with minimal intrusion or interference with his or her rights. Carers or nominated third parties must be consulted and agree that the person would want to join an approved research project.

4.38 ***Offence of Ill-Treatment or Neglect.*** The Act introduces a new criminal offence of ill treatment or neglect of a person who lacks capacity. A person found guilty of such an offence may be liable to imprisonment for a term of up to five years.

4.39 ***Court of Protection and Public Guardian.*** The Act creates two new public bodies to support the statutory framework, both of which will be designed around the needs of those who lack capacity. A new Court of Protection will be created for England and Wales – and there will be a Public Guardian to register and supervise attorneys and deputies.

4.40 It is apparent that the Act applies to a wider constituency than people with a mental health need. There is a presumption of autonomy and a tolerance of unwise decisions. In particular, just because a person suffers from a mental disorder does not mean that his decision-making is impaired and this must be tested separately. Only those who cannot meet the capacity test for that decision are included.

Principles-Based Mental Health Legislation – Recent Developments

4.41 Since the last major review of legislation in the United Kingdom more than 20 years ago, there have been important conceptual shifts in thinking about the basis for compulsory interventions for people with mental disorder. The Richardson Report, reviewing the 1983 Act in England and Wales, was very clear about recommending an ethical, principled base which would have followed many of the provisions since introduced in Scotland, in particular the inclusion of "impaired decision-making" as one of the criteria essential to permit compulsion.

4.42 A different political climate in England and Wales eventually led to the Draft Mental Health Bill 2004, which was not principles-based and was widely regarded as more orientated towards meeting a perceived public protection, rather than a healthcare agenda. For this reason (and because it failed to gain broad enough support to be passed into law) the Review has examined the Mental Health (Care and Treatment) (Scotland) Act 2003, which has actually succeeded in translating a principles base into legislation.

Principles-Based Mental Health Legislation in Scotland

4.43 The MHCT Act 2003 could be seen as "visionary and reversionary" and most of the new provisions flow from the principles. The ethical and practical basis for compulsion was revisited by the Millan Committee and it was recommended that it should be the combination of impaired judgement, risk, and benefit to the patient. As one of the conditions, it must be shown that the patient's ability to make decisions about his or her treatment is significantly impaired by mental disorder.

4.44 Following the principle of "least restrictive alternative" has led to the introduction of Compulsory Treatment Orders (CTOs) which are not limited to a hospital setting but rather meet the person's individual needs for treatment, by specifying measures to be authorised in the care plan. The same level of protections through authorising, monitoring and appeals is ensured for all patients under a CTO, wherever treatment is delivered (hospital or community). The Orders are based on detailed care plans specifying those measures that are required to be compulsory and are authorised through Tribunals, which have been introduced for the first time, replacing the sheriff court, which formerly approved orders. Specified medical treatments are subject to a second opinion and ECT cannot be authorised for a person who has the capacity to consent but declines it.

4.45 Following the principle of reciprocity, the MHCT Act 2003 places obligations on service providers to meet patients' needs for treatment. Treatment is defined very broadly to include nursing care, psychological intervention, and social and educational approaches. Some aspects of treatment plans are recorded as essential, with the obligation for them to be provided open to scrutiny.

4.46 The MHCT Act 2003 introduces new provisions to support of the rights of users of services, including new rights for informal patients, and rights to assessment. The introduction of Advocacy support and the encouragement of the use of Advance Statements for mental health care and treatment are the first in these islands specifically for mental health care.

4.47 Similar provisions apply for patients in the criminal justice system with different threshold criteria for those who present a risk to others, and following the MacLean Committee recommendations, a separate Risk Management Authority has been introduced which takes responsibility for all offenders. There are rights to appeal against excessive security for those treated under the Act, again under the least restrictive principle.

4.48 This legislation has had broad-based support. Problems experienced to date seem largely related to ensuring sufficient workforce to operate the Tribunals, some suggestions of over legalising of the Tribunal hearings with an adversarial rather than a facilitative tone, and the increased professional time required (Presentations to Royal College of Psychiatrists Annual Meeting, July 2006).

The Mental Health and Mental Capacity Legislative Interface

4.49 The two legislative models examined above (Mental Capacity legislation in England and Wales and Mental Health legislation in Scotland) demonstrate how principled-based legislation (dealing with both Capacity and Mental Health), can empower, support and protect persons with mental disorder in those aspects of their care and treatment which require intervention, and also protect others. There is a convergence in the shared importance of decision-making capacity as an essential criterion, with use of the same methods to promote autonomy (participation, advocacy, LPAs, Advance Statements), and a shared emphasis on benefit or best interests.

4.50 While some aspects of the legislation have been observed to be merging conceptually, there are quite separate legal provisions covering their overlapping populations and purposes, and increasingly the interface between separate Mental Health and Capacity legislation is creating confusion. In addition, gaps in protection are being highlighted for those who fall under neither and discrimination is becoming more evident for people experiencing mental illness.

4.51 As described above, Mental Health legislation is strong on protections and provides appeal mechanisms for the two major areas of human rights intrusions which are legalised - deprivation of liberty and treatment for mental disorder without consent or against capacitous refusal. In contrast, Mental Capacity legislation acknowledges that restraint may be necessary but does not develop strong protections around it and at present (until the 2005 Act is amended) prohibits deprivation of liberty from its provisions. It only provides limited protections for treatments.

4.52 There will be situations when a person may fall under both legislations for the treatment respectively of physical and mental disorder, and others where a decision must be taken about which is the appropriate legislation to assess and treat mental disorder. Because the Mental Health statutes in England and Wales and in Scotland are now so different, the interface issues with the relevant Capacity statutes are different too, as are some of the proposed solutions.

The Mental Health and Capacity Legislation Interface in England & Wales

4.53 In England and Wales, the Joint Scrutiny Committee on the Draft Mental Health Bill 2004, which reported in April 2005, emphasised both the confusion reported between Mental Health and Mental Capacity legislation and the need for clarity. The areas specified were: which legislation to use where a person was deprived of liberty in protective care (Bournewood cases) and where treatment without consent for mental disorder was required; and the extent to which advance decisions refusing, and advance statements requesting, medical treatment for mental disorder should be recognised.

4.54 The Code of Practice now describes which Act should be used in particular cases and sets out the implications for people lacking capacity who are also subject to the 1983 Act. Some of the situations described in the Code point to possible injustice as well as confusion. For example, a person who has refused treatment for mental disorder under the 2005 Act, through a valid advance decision, could still be treated under the Mental Health Act, as there are no provisions in that Act to respect such refusals.

4.55 Other situations leave unresolved confusion, for example around Guardianship, where although the powers are available under the 2005 Act, robust protections are not. Depending on the degree of restriction, the person may find himself under one or the other

Act with different rights. The degree of restriction or compulsion also differentiates between the Acts for issues of treatment for mental disorder. If the person is resisting treatment and restraint is needed regularly then the Mental Health Act provisions should be used.

4.56 The difficulties arise mainly from the different bases of the legislation, the different safeguards and protections, but also from the different rights and supports accorded to patients in each. The England and Wales solution appears to hinge around guidance on the nature and degree of restrictions, deprivation of liberty, restraint and force of compulsion. Only some of these problems will be remedied by the Government's proposed amendments to the 1983 Act and the proposed amendments to the 2005 Act to cover deprivation of liberty in Bournewood cases.

The Mental Health and Capacity Legislation Interface in Scotland

4.57 In Scotland, there have been issues identified by a study commissioned prior to the introduction of the MHCT Act 2003 (Gordon J, 2004). For treatment of mental disorder, if the patient lacking capacity does not resist, the AWI Act 2000 is used. Treatment in the community is permitted under both Acts (as treatment may be given under Welfare Guardianship in Scotland) but although the grounds are the same (mental disorder and impaired decision-making ability) they define both of these criteria differently. Similar populations will then come before two different decision-making bodies, the tribunal for mental health cases and the sheriff court for incapacity cases.

4.58 Although both Scottish statutes are principles-based, the emphasis in them is different and difficulties arise from different, and potentially overlapping, definitions of capacity, different decision-making bodies acting at times on the same populations, different rights and safeguards, as well as some overlapping powers.

Gaps and Inequities in Existing Provisions

Deprivation of Liberty in Accepting Persons - Bournewood

4.59 Despite its empowerment agenda, operating the 2005 Act to secure benefit for some people involves unavoidable restrictions to their liberty for their welfare: so this legislation too can be restrictive as well as facilitative. Under Section 6, any restrictions to a person's liberty must be necessary to prevent harm to the person and must be proportionate to the likelihood and seriousness of harm. But there are limits to the restrictions that can be covered by the 2005 Act as it stands and deprivation of liberty is specifically excluded.

4.60 The Bournewood case (Annex 3) highlights the gap in protection for people without capacity who do not object to their deprivation of liberty, but who do not meet the stringent criteria for risk under mental health legislation. In fact, persons lacking capacity in settings other than hospital (like care homes) if their liberty is deprived, also find themselves without due process or appeal mechanisms.

4.61 Following the European Court of Human Rights' ruling, deprivation of liberty (which is now seen as more a matter of degree and intensity than quality of intervention) means "complete and effective control" over the patient's care and treatment. The Government proposes to remedy this gap in England and Wales by amending the 2005 Act (through the MH Bill 2006-2007) and having a system of authorisation using the principles of that Act, and allowing review or appeal, In Scotland, the Scottish Executive is considering whether reform of the AWI Act 2000 is necessary. A solution must be found for Northern Ireland.

Protections for Compulsory Treatment

4.62 Confusion arises as a consequence of apparently having one law for decisions about physical illness and another specifically for mental illness. The simplistic separation of physical and mental illness ignores their complex interplay, accepted in both medicine and philosophy (Matthews E, 1999). For example, should a person who suffers severe depression which affects his/her decision-making capacity because of low levels of thyroid hormone, be treated under Mental Health legislation because it is a mental illness or Capacity legislation because it is due to a physical cause?

4.63 The Code of Practice for the Mental Capacity Act 2005 indicates that it is not actually the origins of the mental illness but the deprivation of liberty and the compulsion required to treat it that is the distinction. However, there is discrimination in this argument, as a person lacking capacity to consent to treatment for a life-threatening physical illness may also need compulsory treatment and have his/her liberty deprived to do so in his/her best interests, but will not be treated under a mental health act and will not be offered the same level of legal protection. In fact, Mental Health legislation has more legal protections for patients through both process and appeal mechanisms and if these types of protections could be afforded through Mental Capacity legislation then both groups of patients, where they lack capacity, could be equally protected in a non-discriminatory way.

Conclusion

4.64 The Review considers that having one law for decisions about physical illness and another for mental illness is anomalous, confusing and unjust.

4.65 Having considered the various problems illustrated above, the Review considers that Northern Ireland should take steps to avoid the discrimination, confusion and gaps created by separately devising two separate statutory approaches, but should rather look to creating a comprehensive legislative framework which would be truly principles-based and non-discriminatory.

CHAPTER 5

DEVELOPING A PRINCIPLES-BASED APPROACH TO LEGISLATION

5.1 The Review considers that the principles introduced in Chapter 1 should underpin all legislative provision, whether that is for what has been previously regarded as "capacity" or "mental health" provisions. These principles are as follows:

Autonomy: respecting the person's capacity to decide and act on his own and his right not to be subject to restraint by others

- There should be an assumption of capacity and provision of care and treatment should be on a partnership and consensual basis, as far as possible. Respect for capacitous decisions should extend to those decisions made legally in advance and where the person grants specific decision-making powers to another on his behalf, for the time when he loses capacity himself.

- Participation - users of services should be fully involved to the extent permitted by the person's capacity, in all aspects of their care, support or treatment. Users of services should be provided with all the information and support necessary to enable them to participate. This may include the involvement of advocates and/or carers. Account should be taken of past and present wishes in so far as these may be ascertained.

Justice: applying the law fairly and equally

- Non-discrimination - persons with a mental disorder or a learning disability should retain the same rights and entitlements as other members of society.

- Equality and respect for diversity - persons should receive treatment, care and support in a way that accords respect for, and is sensitive to their individual abilities, qualities and cultural backgrounds. The legislation should not discriminate on grounds of age, gender, sexual orientation, ethnic group, disability, social class, culture or religion.

- Reciprocity - the loss of a person's rights by detention or by compulsion to treatment and care should be matched by an obligation to provide adequate treatment and care for that person.

- Partnership - services should develop effective partnerships to ensure continuity of care across age and service boundaries.

- Fairness and transparency - there should be fairness and transparency in decision-making, and the right to representation for challenge of due process. Proceedings should be timely.

- The specific rights of children, including the right to education, should be protected.

Benefit: promoting the health, welfare and safety of the person, while having regard to the safety of others

- Where interference is necessary and permissible, the best interests of the person should be protected and promoted, including protection from abuse and exploitation.

- Interventions should only be undertaken using the legislation to achieve benefits which cannot be achieved otherwise. Benefit to the person should include, but not be limited to, reduction of risk of harm to self or others.

Least Harm: acting in a way that minimises the likelihood of harm to the person

- The person should be provided with the necessary care, treatment and support in the least invasive manner and in the least restrictive environment compatible with the delivery of safe and effective care. The perception of the restriction by the person him or herself should be taken into account.

- There should be clear guidance on the use of restrictive practices such as restraint, seclusion and time out for both adults and children, and these should be monitored and subject to evaluative research.

- There should be clear guidance on how and when research may be carried out with persons who have impaired decision-making capacity and this should be monitored.

5.2 Those who provide care to users of services should be accorded due respect for their role and experience, be given appropriate and timely information and advice and have their views and their own needs taken into account.

5.3 The Review considers that these principles of Autonomy, Justice, Benefit and Least Harm underpinning substitute decisions should apply in a non-discriminatory way to both physical and mental health decisions, as well as to welfare and financial needs. Having established an overarching legal Framework using common definitions and a principles-based approach, it should be possible to decide how the essential elements are best served in legislative provision.

5.4 The Review is mindful that any major change will bring forward new situations, dilemmas and interfaces for which solutions must be found. The Review has been able to give consideration to the most fundamental of these and will highlight others. Research and consultation on these will necessarily constitute some of the next phase of the process of reform.

5.5 In the first instance, a number of issues arise from the proposal to include capacity and mental health provisions under the same comprehensive framework including:

a. the further development of capacity law to include those elements presently under separate mental health provisions, while ensuring appropriate protections; and

b. potential difficulties in assessing the capacity of mentally disordered persons to consent to mental healthcare and treatment and of using capacity as the intervention threshold.

5.6 Consideration must then be given to:

a. the interface with Children's legislation; and

b. the consequences of adopting such an approach for forensic patients and the interface with the Criminal Justice System.

5.7 In addition, the practical effects and any potential disadvantages for people with mental disorder as described in the 1986 Order (where the treatment in question is for that mental disorder itself) of moving from the present diagnostic and risk based criteria to a comprehensive approach with a broader definition of the population and principles-based criteria must be examined.

Developing the Law on Substitute Decision-Making to include Assessment and Treatment of Mental Disorder

5.8 It is proposed that decision-making capacity should form the basis of legislative reform. Capacity has an established basis in common law and case law. The Review adopts the definition in the 2005 Act that:

> a person lacks capacity if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain. It does not matter if the impairment or disturbance is permanent or temporary.

The term "impairment of, or disturbance in the functioning of, the mind or brain" subsumes all those conditions presently considered as mental disorder under the 1986 Order, defined as "mental illness, mental handicap and any other disorder or disability of mind". It also includes others due to physical injury or disease such as stroke.

Autonomy and Assessing Decision-Making Capacity

5.9 A test of decision-making capacity will be central to these provisions (Eastman and Dhar, 2000). It must be reliable enough to be compatible with constitutional and human rights principles (Dawson and Szmukler, 2006). There may be concerns about moving from the familiarity of the present "test", which is the "nature and degree of the mental disorder" combined with risk. However, little work has been done on the reliability of present requirements and the significant variations in rates of detention across clinicians, hospitals and regions is likely to reflect variations in application of these traditional criteria (Peay, 2003; Perkins, 2003; Mental Health Commission (NI) Annual Reports; Mental Health Review Tribunal (NI) Annual Reports).

5.10 Both the validity and reliability of any capacity test must be carefully evaluated. Bellhouse et al. 2003, investigated in a naturalistic way the capacity of people to consent to both admission to hospital and treatment for mental disorder and the reliability of the capacity assessments undertaken. Although the study was small, they concluded that decision-making capacity could be reliably assessed and this has been more recently confirmed by Cairns et al. (2005) in a larger study using different assessment methods.

5.11 A mental disorder (as defined in the 1986 Order) may compromise any or all of the abilities required for decision-making. In particular, a person may fail to appreciate how the information applies to his own circumstances through the effects of disorder of mood or delusional thinking (Grisso and Appelbaum, 1998). Failure to "appreciate" is used here in a specific sense, to refer to the person's inability to accept the relevance of his/her disorder or potential treatment consequences for his/her own circumstances; and

- is counted only when choices are based on beliefs which are substantially irrational, unrealistic, or a considerable distortion of reality;
- are consequences of the person's impaired cognition or affect; and
- are relevant to the person's treatment decision.

5.12 Such considerations require that the person's functional abilities must be considered in the context of a mental state assessment, including information from third parties.

5.13 The present test in the 2005 Act, which refers to "understand, retain, use or weigh and communicate the information", does not include "appreciate" and has been considered to have a more cognitive or intellectual bias, reflecting the origins of the legislation. However, developments in the Code of Practice for the Act under the "use or weigh the information" element begin to address this. The Code states, in paragraphs 4.21 and 4.22:

"Sometimes people can understand information but an impairment or disturbance stops them using it. In other cases, the impairment or disturbance leads to a person making a specific decision without understanding or using the information they have been given. For example, a person with the eating disorder anorexia nervosa may understand information about the consequences of not eating. But their compulsion not to eat might be too strong for them to ignore. Some people who have serious brain damage might make impulsive decisions regardless of information they have been given or their understanding of it".

5.14 The Review considers that the test and its elaboration within a Code of Practice should allow adequate consideration to be given to all those aspects of mental functioning which affect decision-making capacity and not just cognitive impairment.

Balancing Autonomy and Protection

5.15 There is an issue as to whether decision-making capacity is a separate assessment without reference to consequences and best interests, or whether, since the decision is task specific (for example, refusal of treatment) a sliding scale or "balance" approach takes the severity of the decision into account and makes a judgement of incapacity more likely as the seriousness of the potential risks for the patient increases. This latter approach has been endorsed by the English courts (Re MB (1997)). It is protective of patients' rights, as there will only be intervention when the person's incapacity to make a decision is held proportionate to the seriousness of the consequences. Recent work (Cairns et al., 2005) has developed thinking in this area and it has also been discussed by others (Gunn et al., 1999; Richardson, 1999; Buchanan, 2004).

5.16 However, this raises concerns about paternalism influencing the decision of the assessing professional under the guise of best interests. With the presumption of autonomy and the protection offered by a documented process to demonstrate substantial impairments balanced with risks, paternalistic decisions are less likely to be made than in the present system. The process will not tell the clinician mechanically what to decide and it should be recognised that in the end a professional judgement must be made.

5.17 Supporting autonomy requires efforts to be made to maximise the person's decision-making capacity. The Code of Practice for the 2005 Act has detailed guidance on the timing of assessments, including "avoid or challenge time limits that are unnecessary if the decision is not urgent. Delaying the decision may enable further steps to be taken to assist people to make the decision for themselves". This would apply to those recovering from the effects of medication or alcohol.

5.18 At other times, clinicians will be required to decide about decision-making capacity in the absence of reliable information. This is often the case in emergencies or when the patient refuses to co-operate. Where other evidence suggests that the person's decision-making is impaired, then the balance is tipped more in favour of benefit and the necessity to act for the person's protection is more evenly balanced. Thus the balancing of autonomy and benefit may need to be judged differently for an assessment period than for treatment.

5.19 If decision-making is the primary criterion, situations of transient or fluctuating loss of capacity, which are common in those with and recovering from mental illness, need consideration. The nature of the impairment of decision-making capacity may need to be taken into account as well as the degree (for example, a rapid cycling mood disorder). It is not necessarily in the best interests of the patient to allow transient, competent treatment refusals which result in a situation of relapse.

5.20 It will be necessary to develop provisions that allow the principle of Benefit sufficient weight to preserve the person's dignity and support his autonomy by allowing continued access to required health care and treatment. For this to happen, a more sustained period of regained capacity may be required, while allowing the patient the right of appeal. Present provisions authorising intervention for limited periods of time before review and renewal is such a mechanism. A Code of Practice should give detailed guidance on this matter so that the spirit of the principles is adhered to.

5.21 The person with a known pattern of illness whose condition is deteriorating presents a particular challenge as to when to intervene in his best interests. In such situations, a treatment plan made with the person when he has capacity would inform the judgement about best interests and if it was formulated in an Advance Statement or Lasting Power of Attorney was given, then these would be respected as equivalent to the person having capacity to make the decision.

Applying the Principles

5.22 The principle of Autonomy includes participation in decision-making and expects that every effort and support is provided to encourage and enable the person with mental disorder to access mental health care and therapeutic interventions on a voluntary basis. Developments in community-based services with intensive home-based treatment and assertive outreach teams work on this basis. As in the 2005 Act, there should be a presumption of capacity and participation in decision-making supported at all levels.

5.23 Under a principles-based approach, interference with a person's decision-making, his liberty and his person on health grounds can only be justified if, despite such support:

- the individual's autonomy is compromised by impairment of, or disturbance in functioning of, mind or brain to the extent that he lacks decision-making capacity with respect to the particular risks at issue;

- any intervention is designed and intended for his benefit; and

- interventions are the least restrictive and least invasive of the options available.

5.24 In addition and, in particular, where the person objects and powers are required to prevent significant harm to the person or others, under the principle of Justice legislation should require that:

- interventions are non-discriminatory, fair and allow appeal;
- interventions to prevent harm are proportionate;
- rights removed are compensated for by appropriate services for both adults and children; and
- adequate, proportionate and timely protections are offered at all stages.

These conditions must then be translated into workable definitions, criteria and procedures.

Definition and Criteria

5.25 It is important to ensure that introducing a change of approach addresses current problems and serves the people who need it, and that it is neither over inclusive nor excessively narrow in its interpretation and operation. The practical consequences of introducing a capacity-based approach must be anticipated.

5.26 The present assessment criteria for the need for treatment of mental disorder comprise a broad definition - "mental disorder", qualified by "of a nature or degree which warrants his detention in hospital for assessment", and the likely consequences - "failure to so detain him would create a substantial risk of serious physical harm to himself or to other persons".

5.27 This would change to a broad definition - "impairment of, or disturbance in functioning of, mind or brain" qualified by "which significantly affects his decision-making capacity"; and the likely consequences - "failure to assess would create a significant risk to the health, safety or welfare of the person or to the safety of others". The latter element is very similar to the criteria in Scotland, although they retain the term "mental disorder" and use the term "impaired decision-making ability".

5.28 The use of the criterion "significantly affects decision-making capacity" aims to clarify and emphasise the most significant effect of the "impairment of, or disturbance in functioning of, mind or brain". As described above, it moves from the very imprecise "mental disorder of a nature or degree which warrants detention" to a more focused judgement. It should strengthen the grounds for challenge while acknowledging that, by their very nature, many of these assessments will require finely balanced clinical judgement.

Developments Required from the Principles

5.29 For intervention purposes, additional principles come into play. The principle of Benefit will demand that the proposed treatment intervention is an individualised care plan which takes into account what the person would likely want for himself, through his expressed or implied own wishes. It should be of benefit to the whole person and requires, therefore, that care plans for the treatment of mental disorder are holistic in their approach and content, with psychological and social elements balanced appropriately with medical treatments. This will require the involvement of a number of different professionals, and users of services should expect to play as full a part as they are able in devising this. This is in keeping with developing good practice, which emphasises a partnership approach Further development of the principle of Autonomy will include taking account of advance statements, preferably developed by users of services with their treating mental health team. Evidence of involvement of users of services in developing their care plans should be part of the process.

5.30 The principle of Reciprocity requires services to provide the programme of treatment and care with which individuals are obliged to comply. Service development must be in tandem with legislative change otherwise this may lead to a perverse incentive with inequity for voluntary patients, which must be avoided. Realistically too, it may not always be possible for every element of a programme of treatment to be available immediately and the Code should give guidance on how this principle is to be respected. In Scotland, there is a right of referral to the tribunal if the designated essential elements are not provided.

5.31 The principle of Least Harm requires the least restrictive alternative with respect to the assessment and treatment setting and the use of the least invasive treatment. Planned developments in services with intensive supports, such as Home Treatment Teams and

Assertive Outreach Teams, use a collaborative approach which should reduce the use of compulsory powers and the perception of coercion (Davidson G. and Campbell J., 2007). However, where such powers are needed to support a care plan, consideration must be given to this principle and the least restrictive setting may be the place the person lives, in the community.

5.32 Treatment in a community setting is not a completely new concept in Northern Ireland. There already exists a provision to enable treatment to be continued in a community setting under Article 15 of the 1986 Order. Detained patients may be granted leave from hospital under conditions specified by the RMO and this may be renewed on a monthly basis with notification to the Mental Health Commission. Welfare may be protected through the powers of Guardianship in the community.

5.33 Users of mental health services have a number of concerns regarding the introduction of community-based compulsory treatment. In order to deliver a holistic approach and avoid over-reliance on medication (see paragraph 5.28) community-based psychological and social support services should be introduced before the legislation. Again, mechanisms referred to in paragraph 5.29 to ensure that the principle of reciprocity is met will have particular reference here.

5.34 While the home-based setting may appear the least restrictive, the benefit provided will depend on the person's circumstances and the impact on the family. Their role with respect to care and compulsory treatment will need to be considered in each case.

5.35 Users of services are concerned that measures to extend powers to treatment in the community might continue to be enforced when they have regained capacity. Special protective arrangements will need to be incorporated to ensure a re-assessment for those treatments specified under the legislation, or if requested by an advocate or attorney.

5.36 It is acknowledged that it is very difficult to establish a reliable evidence base for the efficacy of community-based treatments. This is partly because of methodological problems (for example, because legislative models and services differ so much) but also ethical problems in such research (Churchill R. et al., 2006). Important for this review is to balance all the principles, being mindful of the overall benefit to users of services. In this regard, when the views and experiences of stakeholders are examined, it appears that some versions may be more viable in restricted and controlled environments, eg. the New Zealand experience (Gibbs A. et al., 2006).

5.37 The principles-based model proposed is most similar to Scotland, where powers to assess and treat have effect in the most appropriate and least restrictive setting (community or hospital) with the necessary protections. The Review is encouraged by the early reports from Scotland on the use of these powers and an independent study by the King's Fund on Community-Based Compulsory Treatment Orders (Lawton-Smith, 2006). The provision, although considered bureaucratic by professionals, was generally welcomed and appeared to be used at present mainly for those relapsing patients who deteriorated in their health following non-engagement. Although there were concerns expressed about resources likely to be required in future, the tone was one of "cautious optimism". A short summary of this provision in Scotland is described in Annex 4.

Consequences of Changing the Definitions and Criteria

5.38 Under the 1986 Order there is an exclusion in the definition of mental disorder for "by reason only of personality disorder". Persons with personality disorder fall within the Review's proposed definition "impairment of, or disturbance in the functioning of, the mind or brain" which would be new in Northern Ireland. Persons with this condition should not be discriminated against by exclusion. Nevertheless, it is unlikely that many would meet the necessary criterion of significantly impaired decision-making capacity.

5.39 Experience in Scotland suggests that personality disorder on its own is very rarely considered to be associated with significant impairment of decision-making ability under their legislation. In addition, the conditions for compulsory treatment would include the requirement that it is for the person's benefit and that this cannot be provided any other way. For people with personality disorder the use of compulsory powers is likely to be counter-therapeutic.

5.40 Using the proposed criterion of decision-making capacity has implications for other people currently not protected in law, those who have a mental disorder and lack decision-making capacity but, because they do not object or pose a substantial risk of serious physical harm, are treated informally and, therefore, without protections. Likewise, persons who lack capacity and are objecting to treatment but who pose a risk of serious psychological harm to themselves or others cannot be treated under present legislation. Under this approach they would be included if they can benefit from treatment.

5.41 The Review notes the research evidence in this area (Bellhouse et al., 2003) which suggests that only a small number of those currently detained under Mental Health legislation in England and Wales are found to retain capacity and would not, therefore, be included in this approach. The majority of the population currently eligible for detention for treatment would meet the new criteria. Likewise, those patients without capacity referred to above, currently treated "voluntarily" and not protected, would be included.

5.42 For persons with learning disability, the proposed criteria should respect their decision-making capacity when it is present and treat them in the same way as the rest of the population, allowing access to care and treatment and permitting protection as required.

5.43 The proposed application of a capacity approach to interventions should be the focus for early local evaluation. The training needs and practicalities surrounding capacity assessment in clinical and other settings should be evaluated in advance of any proposed introduction of legislation.

Children and Young People with Mental Illness or Learning Disability

5.44 Legislation for mental disorders which is based on substitute decision-making has particular implications for the interface with Children's legislation since children reach decision-making capacity at different stages in their development, their parents have special rights and responsibilities with regard to them and there already is legislation which applies to welfare. The principles and recommendations of the Review's Report, A Vision of a Comprehensive Child and Adolescent Mental Health Service (2006), provide the basis for children's services. A small number of children and young people will also require the support of specific legislation and the proposed principles for legislation recognise their particular needs.

Welfare and Services

5.45 The Children (Northern Ireland) Order 1995 (the Children Order) brings together in a single coherent statutory framework most of the public and private law relating to the care, upbringing and protection of children. This legislation is principles-based and the welfare of the child is paramount. It is strongly influenced by both the European Convention for the Protection of Human Rights and Fundamental Freedoms 1950 and by the UN Convention on the Rights of the Child 1989 (the UNCRC).

5.46 Whilst the language and emphasis is somewhat different, the principles adopted are very similar to those proposed by this Review. For example, the Children Order incorporates a best interests test for any intervention and it demands the least restrictive option and proportionality by its insistence upon a "No Order" principle. Respect is shown for the dignity and autonomy of the child and his or her family by an obligation to include them in decision-making. While it allows effective protection, it balances this with the opportunity to challenge such intervention. The principle of least harm is reflected in the requirement to avoid unnecessary delay in proceedings. Reciprocity is found in the obligation to provide appropriate services to the child's assessed need. The Children Order permits restriction and deprivation of liberty in very limited circumstances by authorising the child to be kept in secure accommodation, provided specific criteria are established, and only as an option of last resort.

Healthcare and Consent to Treatment

5.47 Under the Children Order, health is defined as physical or mental health. Harm means, among other things, the impairment of health or development, and development is defined as physical, intellectual, emotional, social or behavioural development. Consent to treatment for children and young people is a very complex area, with elements from common law, statute, case law, and the Court's inherent jurisdiction.

5.48 The Age of Majority Act (Northern Ireland) 1969 creates a statutory presumption that young people over the age of 16 are capable of giving consent to any surgical, medical or dental treatment, as is any adult. However, children under the age of 16 may also be capable of consenting to medical treatment, if they are of "sufficient understanding and intelligence to understand fully what is being proposed". Case law since the original ruling has tended to demand a more rigorous test for children than adults.

5.49 The implications of a capacity approach to all substitute decision-making legislation would require the same basic approach to be applied for children. While most people would agree that parents be substitute decision-makers for children up to the age of 10 or 12, consideration might be given to a rebuttable presumption of capacity between 12 and 16. When a young person is deemed to lack capacity, parents would ordinarily have substitute powers until the age of 16. However, if the child's best interests are considered to be at significant risk then treatment may have to be authorised.

5.50 New capacity-based legislation would allow all the protections afforded to adults in these situations, for example, if such an assessment or treatment plan involved significant restrictions or deprivation of liberty regardless of whether the child is compliant or objecting. If parents' views are to be over-ridden, or if the child has no parent and no parental responsibility has been given, the special needs of the child must be recognised and protected in arrangements for advocacy and representation.

5.51 Children should be involved in their care planning and treatment as much as possible, in an age-appropriate manner. A special situation arises with respect to Advance Statements about treatment. While the consideration of a young person's known wishes about care and treatment should be respected as part of devising his treatment plan, such statements would only have legal validity from the age of 16 (as in the 2005 Act).

Special Protections for Children and Young People

5.52 The special vulnerabilities and developmental needs of all those children and young people under the age of 18 years who may fall under the proposed approach to substitute decision-making will require special rights and protections.

Services

- Children must be assured of their right to services, including accommodation, appropriate to their age and needs.
- Children must be assured of their right to education.

Participation and Representation

- Children must be able to participiple in decision-making, for example through appropriate Advocacy services.
- Children must be provided with appropriate and accessible information.
- Children must be entitled to be represented at Tribunal hearings by appropriately trained representatives.
- Advance Statements and Refusals should only apply to persons over age 16 years.

Protections

- Periods of compulsory treatment for mental illness for children shall, without prejudice to the child, be disregarded for certain purposes (otherwise than in legal proceedings) when that child becomes an adult.

- Guidance on restrictive practices such as restraint and other deprivations of liberty should include specific reference as to how these might be applied to children and young people in accordance with the United Nations Convention on the Rights of the Child.

- Monitoring bodies should liaise and, where appropriate, work in partnership to ensure that the rights of children and young people for protection continue to be met.

Interfaces with the Criminal Justice System

5.53 People who have decision-making capacity should be free to make their own decisions. If those decisions are unwise or imprudent, or if they result in a crime, then those individuals must take responsibility for the decisions they have made. The principles-based approach cannot excuse people who have decision-making capacity from the consequences of their decisions. Similarly, this approach cannot impose compulsion or restriction on people who have decision-making capacity, even where they are considered to pose a risk of serious harm to the public. Instead, the necessary provisions and protections must be made under Criminal Justice legislation. There are, therefore, important interfaces with the Criminal Justice System which require further consideration.

5.54 Currently in Northern Ireland there is a complex interplay between the Criminal Justice System and the Health and Social Services. Criminal law recognises that individuals may suffer from mental disorders that, for example, excuse or reduce their responsibility for their acts or omissions or that impair their ability to participate in criminal proceedings. The present legal framework, including the 1986 Order, includes a range of measures to facilitate the treatment and care of people suffering from mental disorder. Mental health and learning disability services are provided or being developed for people who are subject to the Criminal Justice System such as people in prison, in contact with the police, on bail, attending court or on probation. The Review supports a joint co-operative interagency approach that both meets the requirements of the Criminal Justice System while ensuring appropriate provision to meet healthcare needs (Forensic Services Report, 2006).

5.55 The proposed legislative Framework which integrates Capacity and Mental Health legislation should be applicable to all people in society, including those who are subject to the Criminal Justice System. It must integrate with the Criminal Justice legislation, for example with the law on criminal responsibility, unfitness to plead and unfitness to stand trial; it must contain a suitable range of disposal options for the courts and it must facilitate assessment and treatment, for example by providing for the transfer of mentally disordered prisoners to hospital.

5.56 Many individuals who are subject to the Criminal Justice System have mental health and learning disability needs. The Review supports the Principle of Equivalence (Forensic Services Report, 2006) which states that people who are subject to the Criminal Justice System should have access to assessment, treatment and care that is equivalent to that available to people in the rest of our society. The principles-based approach to legislative reform requires that those who have decision making capacity should have access to services on a voluntary basis and there should also be a range of measures, underpinned by legislation, that ensure appropriate provision for those whose decision-making capacity is impaired.

Public Protection

5.57 The new legislative Framework must contain measures that help protect members of society against harm from people whose decision-making capacity is impaired in such a way as to make the person a risk to others. These measures must integrate with the other public protection arrangements and must not discriminate unjustifiably against people who suffer from mental health or learning disability problems. There is widespread concern in society about crime and violence and it appears that there are frequent misconceptions about the contributions made by people suffering from mental health and learning disability problems.

5.58 People who suffer from the more serious forms of mental illness or learning disability can, like other members of society, commit crimes but their overall contribution to crime is small. The vast majority of people with mental illness are no more likely than anyone else to commit a violent crime (Mental Health Commission, New Zealand, 2002). The greatest risk of harm that is posed by people with mental illness is to themselves rather than to others.

5.59 Nevertheless, there is a modest link between mental illness and violence, particularly in some individuals who are currently experiencing symptoms of severe mental illness, not using effective medication and abusing alcohol and/or drugs. In such cases violence can be a reflection of insufficient treatment and support services (Mullan P.E. 1997). Research has shown that people who abuse alcohol and other substances and people who suffer from certain categories of personality disorder are at increased risk of committing crime.

5.60 At present in Northern Ireland, when an individual who is suffering from mental disorder has committed or appears to have committed a crime and has posed a risk to others, there is generally a response both by the Criminal Justice System and by mental health or learning disability services. Additional measures to help protect the public against violence have been introduced in adjoining jurisdictions.

5.61 In England and Wales, Multi-Agency Public Protection Arrangements were introduced in 2000 (Criminal Justice and Court Services Act 2000) and strengthened in 2003 (Criminal Justice Act 2003). These require the police, prison and probation services to work together to assess and manage the risks posed by sexual and violent offenders.

5.62 In Scotland, the interface between proposals for new Mental Health legislation and proposed measures to protect the public from serious violent and sexual offenders was addressed by two contemporaneous reviews - while the Millan Committee was reviewing the Mental Health legislation, the MacLean Committee reviewed the arrangements for managing serious violent and sexual offenders.

5.63 The MacLean Committee made a range of proposals to address the assessment and management of risk. These included the introduction of a Risk Management Order, a new sentence – an Order for Lifelong Restriction - and the establishment of a Risk Management Authority, whose remit included developing policy, conducting research, setting standards, issuing guidance, accrediting practitioners and approving and monitoring risk management plans. These proposals complemented the proposals from the Millan Committee for new mental health legislation.

5.64 In Northern Ireland, there has been no equivalent of the MacLean Committee that has brought together a wide range of proposals to address the management of serious violent and sexual offenders although there have been a number of recent developments and proposals to improve measures to protect the public from offenders who have committed serious violent and sexual offences. These include the creation of the Life Sentence Review Commission, proposals to extend the current remit of the Multi-Agency Procedures for the Assessment and Management of Sex Offenders (MASRAM) to include violent offenders and proposals in the Review of the Sentencing Framework to introduce a discretionary release to ensure that dangerous offenders are not released until their risk is such that they can be safely supervised in the community.

5.65 The Review supports the development of an inter-agency risk assessment and management framework that applies to all offenders who pose a prescribed level of risk and irrespective of whether or not these individuals suffer from mental health or learning disability problems. It is essential, therefore, that the new legislative Framework interfaces effectively with existing Criminal Justice legislation and with developments in the Criminal Justice System.

Criminal Responsibility and Capacity to Participate in Legal Proceedings

5.66 Criminal law recognises certain psychiatric defences which serve to excuse or reduce the criminal responsibility of an accused person for his or her actions or omissions. These defences include "insanity" and "impaired mental responsibility".

5.67 The legal term "insanity" is included in the 1986 Order and in the Criminal Justice (Northern Ireland) Order 1996, but is now outmoded and does not correspond to any recognised clinical entity. It is stigmatising and promotes negative and unhelpful connotations of mental health and learning disability problems. It should be reviewed. A similar review by the Scottish Law Commission recommended that "insanity" be replaced by 'lack of responsibility by reason of mental disorder' (SLC Report, 2004).

5.68 The psychiatric defence of impaired mental responsibility may be invoked in homicide cases. In practice it causes substantial uncertainty and confusion. It would benefit from being reviewed, particularly with a view to giving greater guidance to clinicians, lawyers and the Courts on the correlation between legal and clinical definitions and conditions. Recommendations for review of the legal provisions in relation to mental responsibility and homicide have been made in England and Wales (The Law Commission, Murder, Manslaughter and Infanticide, Law Com No 304, 2006) and in Scotland (SLC Report, 2004).

5.69 Criminal law also recognises that an accused person may suffer from a mental disorder that renders him unfit to plead or unfit to stand trial. It appears that in cases of unfitness to plead or unfitness to be tried, the range of disposals available to the Courts (as determined by the 1986 Order and the Criminal Justice (Northern Ireland) Order 1996) may not adequately address the range of clinical conditions and circumstances that may present. For example, individuals with certain types of brain damage may be unable to instruct their legal advisors and may thus, under the current provisions, be deemed unfit to plead.

5.70 However, the current range of disposals available to the Courts, namely a hospital order with or without restriction, a guardianship order, a supervision and treatment order and an absolute discharge, may not adequately meet the clinical needs of the individual and the requirements of the Criminal Justice System. The proposed new Framework provides an opportunity to improve on the current arrangements.

CHAPTER 6

A PROPOSED COMPREHENSIVE FRAMEWORK FOR SUBSTITUTE DECISION-MAKING

Introduction

6.1 The key proposal for statutory reform is that Government should adopt a coherent and co-ordinated approach to legislative provision. This should be through the introduction of comprehensive provisions for all people who require substitute decision-making. A single legislative Framework is proposed for interventions in *all* aspects of the needs of people requiring substitute decision-making, including mental health, physical health, welfare or financial needs. Such a comprehensive Framework ("the Framework") is described throughout this Chapter, while a model application of the Framework ("the Model") is presented in Chapter 7.

6.2 The proposals contained within this and the next Chapter are not an attempt at legislative drafting, but a description and an explanation of what is considered necessary for reforming existing provision and as an aid to consultation. Detailed consideration is given to the principal situations in which the Framework might apply and how it should operate in practice.

6.3 Where there is concern about a person's capacity to make a particular (and necessary) decision, an assessment of capacity should be carried out. If it is established that the person does have capacity to make the decision, then his/her decision must be respected. If the person is found not to have decision-making capacity, however, the decision may be made by others on his/her behalf and any resulting supportive actions carried out. The Framework applies only to persons whose decision-making capacity is impaired.

6.4 The great majority of substitute decisions and support provided to people unable to make a decision for themselves should be arranged informally, through discussion and with the agreement of all interested parties. Where there is doubt about the extent of protection afforded to people who act with such *general authority*, however, or where more serious and/or intrusive procedures are proposed, it will be necessary to seek, and to operate under, a measure of *formal authority* – ultimately, in the form of *specific authorisation*. Safeguards should be introduced for each of the latter two levels of authorisation through the Health and Social Care Trusts, the Regulation and Quality Improvement Authority (the RQIA) and the Mental Health Review Tribunal. Thus, for example, proposals for a person's care and support should be approved by the Trusts, and those which require formal *Intervention Plans* (see below, paragraphs 6.19 and 6.20) should be independently assured (from each of the clinical, social and legal perspectives) by the RQIA. The Tribunal is best constituted to determine the legality of the particular situations, if required.

Legislative Basis of the Framework

6.5 The Framework is based on the 2005 Act, considered in detail in Chapter 4, and is underpinned by a set of fundamental principles (Autonomy, Justice, Benefit and Least Harm, as at paragraph 5.1). The majority of the key provisions of the 2005 Act should be adopted in Northern Ireland, with minimal amendment. These include:

- definitions of *decision-making capacity* and *persons with impaired decision-making capacity*;
- requirements that any decision or action undertaken on behalf of a person with impaired decision-making capacity must be in his/her *best interests* and must have regard for the *least restrictive* option available;
- legal protection for the performance of (everyday) acts carried out in connection with a person's care or treatment;
- provision for *attorneys (acting under new LPAs)*, to deal with welfare (including healthcare) in addition to property and finance;
- an enlarged jurisdiction of the Court in relation to welfare, healthcare and financial matters;
- powers of the Court to make declarations and orders, and to appoint deputies;
- the recognition of *advance decisions* to refuse treatment and, in addition, *advance statements* about preferred treatment;
- safeguards in relation to research involving persons with impaired decision-making capacity;
- the provision of the services of *independent advocates*, including for persons who have no other support from family or friends;
- the issue of *Codes of Practice* to provide guidance to all those working with and/or caring for persons who have impaired decision-making capacity, including family members and carers;
- a new offence of ill-treatment or neglect of persons with impaired decision-making capacity;
- the creation of a new statutory office of the *Public Guardian*, with responsibilities to include dealing with representations and/or complaints about deputies appointed by the Court and attorneys; and
- ratification of the Convention on the International Protection of Adults.

6.6 The following provisions, which are not within the 2005 Act, although some of which are currently defined in Mental Health law, should be included within the proposed legislative Framework:

- compulsory admission to an approved facility for assessment;
- compulsory detention in hospital for treatment;
- interventions involving supervised care or treatment in the community;
- a system for risk assessment and the management of persons who pose a risk to themselves or others by reason of mental disorder;
- the provision of clearly defined procedures and protections for prolonged and particularly serious interventions;
- an enhancement of the role and functions of the present Mental Health Commission, which will transfer to the Regulation and Quality Improvement Authority (the RQIA);
- a development of the role and functions of the Mental Health Review Tribunal;
- the introduction of a *nominated person* as a replacement for the "nearest relative", with a re-definition of the corresponding role;
- an enhancement of the role and recognition of the rights of carers;
- an extension of certain professional boundaries and functions, with the creation of two new professional offices, the *Approved Clinician* and the *Responsible Clinician*; and
- ratification of the Convention on the Rights of Persons with Disabilities.

6.7 The Framework makes provision for the legal protection of those compliant persons with impaired decision-making capacity ("Bournewood" situations). It also allows for future development of provisions to further protect vulnerable adults from abuse and neglect.

The Principles Base

6.8 The Framework seeks to remain true to all four of the fundamental principles identified in Chapter 1 and elaborated upon in Chapter 5 – Autonomy, Justice, Benefit and Least Harm – while at the same time recognising that specific situations may at times draw different sets of these principles into varying degrees of tension.

6.9 The starting-point for the Framework is a presumption of autonomy, such that people with capacity to make their own decisions have a right to have those decisions respected by others. Substitute decisions may be made on behalf only of persons who do not have (or who are at least reasonably believed not to have) the capacity to make a specific decision (or decisions) at a specific point in time.

6.10 This means that the common law should apply to people with decision-making capacity, whereas new capacity-based provision is required for those persons with impaired decision-making capacity.

6.11 The Framework assumes that all necessary supports and enhancements to enable people to have as much control as possible over decisions about their own lives should be made available and accorded due legitimacy in the decision-making process. Such supports include the appointment of attorneys, advance decisions (to refuse interventions) and advance statements (about preferred interventions), and trained and accredited independent advocates.

6.12 The Framework also assumes that, before any decision or intervention is undertaken on behalf of someone who has (or is believed to have) impaired decision-making capacity, steps will have been taken to ensure that such are in the person's best interests, and that regard will have been given to the least restrictive alternative.

Scope of the Framework

6.13 The Framework is intended to apply in situations where (i) a decision requires to be made on a specific matter in relation to a particular person, and (ii) there are grounds to suspect that the person may not have the capacity to make that decision. Specifically, it permits intervention in the lives only of persons whose capacity to make a decision for themselves is impaired at that time because of "an impairment of, or a disturbance in the functioning of, the mind or brain" (*cf*., section 2 of the 2005 Act). For convenience, such persons will be referred to collectively throughout the remainder of this Chapter as "persons with impaired decision-making capacity".

6.14 As already noted, the Framework incorporates and extends many aspects of the 2005 Act. Specifically, it will support and empower persons with impaired decision-making capacity by:

- defining the concept of impaired decision-making capacity in such a way as to balance all aspects of the decision-making process (see above, paragraphs 5.11 to 5.13), with the resulting definition elaborated upon in a Code of Practice;
- incorporating a "best interests" test, identical to that detailed in section 4 of the 2005 Act;
- requiring that, before any action or decision is taken, regard must be given to whether its purpose can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action (cf., section 1(6) of the 2005 Act); and
- incorporating a hierarchy of powers and protections which relate proportionately to the degree of interference with the person's autonomy (including any significant restrictions upon, or deprivation of, his/her liberty) on the one hand, and a need to recognise and respect the person's dignity on the other.

6.15 Such a proportionate hierarchy of powers and protections is rooted firmly in the principle of least restriction. This means that assessments, for example, should be carried out voluntarily and in the most appropriate setting available, with services provided in the person's local environment if at all possible (*cf.*, the Review's Report, A Strategic Framework for Adult Mental Health Services (June 2005)). The use of intensive supports in this way may avoid the need for compulsory powers.

6.16 The Framework is intended to apply to substitute decision-making on behalf of *all* persons with impaired decision-making capacity, including those whose decision-making is impaired as a result of a mental disorder – irrespective of whether that impairment is permanent or on a fluctuating or temporary basis, e.g. due to a recurrent mental illness (see above, paragraph 5.18) – and with equivalence for those who are subject to the criminal justice system.

6.17 It does not extend to people who have a mental disorder but whose decision-making capacity is not impaired. As such, it is essential that the Framework be seen as just one aspect of a comprehensive reform and modernisation of *all* parts of the system of care and treatment for people with a mental disorder, irrespective of whether they have impaired decision-making capacity.

6.18 It is contemplated that the Framework will provide for all aspects of a person's needs, including those which relate to issues of property and finance. However, the greater part of the proposals in this Chapter will relate to decisions in respect of (all) health and welfare needs.

Interventions and Intervention Plans

6.19 In recognition of both a broader applicability of the Framework and also of the fact that, in practice, many situations involve a combination of health and welfare elements, the term *intervention* (rather than "care" or "treatment") will generally be used to indicate those actions which are undertaken on behalf of a person with impaired decision-making capacity. Interventions include actions in relation to medical, nursing, psychological or care needs, habilitation or rehabilitation (including education and training in work, social and independent living skills) and specific welfare arrangements.

6.20 Where a proposed intervention is sufficiently serious and/or intrusive, it will need to be approved by the Trust and independent assurance sought from the RQIA (see above, paragraph 6.4). Full details must be submitted in the form of an *Intervention Plan* (see paragraph 6.21 on the content of Intervention Plans, and 6.30 on the need for them to be submitted to the RQIA for assurance). The RQIA will be empowered to require Trusts to take action if the Trust fails to act on its advice and the Tribunal will be in a position to take a legal view if interventions are challenged. An Intervention Plan will be prepared after full consultation with and, wherever possible, the agreement of, the person, his/her representatives and carers and any other interested parties, including any professional or multi-disciplinary team who will be responsible for providing the resulting intervention.

6.21 The content of Intervention Plans will obviously vary, depending upon individual circumstances. As a minimum, it is anticipated that all Intervention Plans will include the following:

- a declaration from the Responsible Clinician that:
    - the person's capacity to make a decision for him/herself is impaired because of "an impairment of, or a disturbance in the functioning of, the mind or brain" (and with the most likely reason(s) for such impairment clearly indicated);
    - any proposed decision or intervention has been exposed to a rigorous application of the Framework principles, in particular those of the person's best interests and the least restrictive alternative;
    - the proposed intervention is available and is likely either to prevent the person's condition from worsening, or to alleviate its symptoms or effects;
    - if the proposed intervention was not to be provided, there would be a significant risk to either (i) the health, safety or welfare of the person or the safety of others or (ii) the person and/or others of serious harm (as appropriate – see paragraph 7.31); and
    - the intervention could not be provided without the authorisation of the proposed Intervention Plan;
- full details of the person's assessed needs and the nature of the proposed intervention, which will generally be in the form of a multi-disciplinary care plan, including any elements of significant restriction and/or deprivation of liberty;
- details of the setting in which the intervention is to be carried out (i.e. in a community setting or an approved facility); and
- details of the rights of the person (and/or of his/her representative) to appeal against the Intervention Plan.

6.22 Those components of an Intervention Plan which are considered essential should be indicated as such, and there will be a responsibility on service-providers for these to be provided.

Balancing Powers and Protections

6.23 Persons with impaired decision-making capacity may be vulnerable in certain situations and in a variety of ways. So, in addition to promoting autonomy, strong provisions aimed at protecting a person's dignity and human rights must be included within the Framework. Measures should be provided within law to protect individuals from the consequences of both their own harmful actions, or lack of action, and the actions of others.

6.24 Interventions should be founded only on proportionate legal process. For those with impaired decision-making capacity who are unable or unwilling to agree to such interventions, there should be adequate and timely arrangements for appeal to an appropriate judicial forum with the support of advocates and/or carers. Proceedings should not be unduly adversarial, but should allow for a just hearing in a facilitating environment, similar to a sitting Family Court.

6.25 As already indicated, a proportionate relationship should exist between any interventions which may be performed by way of the Framework and its associated protections: the more intrusive and significant the intervention proposed in relation to a person with impaired decision-making capacity, the greater the degree of safeguards he/she should be afforded. At the highest level of protection, this should include automatic judicial review.

6.26 Likewise, the Framework seeks to ensure that persons who either withhold their co-operation or otherwise do not consent to a proposed intervention, either verbally or by way of their behaviour, should also be afforded an appropriate and proportionate level of protection.

Judicial and Administrative Provisions

6.27 The ultimate source of judicial authority in relation to any issues affecting persons with impaired decision-making capacity in Northern Ireland should continue to be the High Court. It is not considered either necessary or appropriate in a small jurisdiction to create a separate Court of Protection. Responsibility for the disposal of Court business at appropriate venues and by assigned Judges, Masters or other judicial officers may properly be determined by the Lord Chief Justice.

6.28 The appointment of a Public Guardian for Northern Ireland, similar to that being introduced in England and Wales (see above, paragraph 4.39), would provide the support required to ensure the proper discharge of responsibilities granted to deputies and others by Court Orders, to register Powers of Attorney and supervise the role of attorneys, and to deal with enquiries and the investigation of complaints. The Public Guardian would also assist in seeking to resolve disputes or disagreements between persons with impaired decision-making capacity, their representatives and other interested parties without recourse to proceedings before the Court.

6.29 In a limited number of situations, there will be a need to provide appropriate intervention for persons with impaired decision-making capacity which involves significant infringements of their liberty and autonomy. It is proposed that the special protections now prescribed in Parts II, III and IV of the 1986 Order should be replaced by a requirement that an Intervention Plan should be prepared in any case where it is proposed to:

- admit the person compulsorily to an approved facility for assessment and/or ongoing intervention;
- introduce an intervention which involves either a significant restriction upon, or a

deprivation of, a person's liberty (albeit excluding those individuals considered as *Bournewood* cases, for which separate provision will be made – see paragraph 7.45); or

- introduce certain "prolonged or particularly serious interventions" (see below, paragraphs 7.54 to 7.58).

6.30 In all such cases, a copy of the Intervention Plan should be submitted for assurance to the designated independent monitoring and regulation body, the RQIA, which is to assume responsibility for the functions of the current Mental Health Commission.

6.31 The RQIA should be concerned not just with persons who are subject to compulsory detention. It should also monitor and regulate all aspects of services provided to people with a mental disorder, irrespective of their location (i.e. in the community, hospital or prison) and also of whether or not they have decision-making capacity. Specifically, in addition to those functions specified in the 1986 Order, the RQIA should:

- monitor the implementation of Good Practice Guidelines in relation to the Framework – to include guidance on what will constitute acts which involve either *significant restriction* upon, and/or *deprivation* of, a person's liberty;

- protect the interests and promote the well-being of all persons with impaired decision-making capacity, by keeping their treatment and care, including the use of any compulsory powers and general restrictions (i.e. those that might be imposed in any particular setting for the common good), under regular review;

- assure all Intervention Plans; and

- monitor the effective operation of all new legislation.

6.32 Finally, an independent *Tribunal* should be established as the specialist judicial forum with responsibility to review and hear appeals with regard to the legality of Intervention Plans. It should be open to the person him/herself, the RQIA or any representative of the person with impaired decision-making capacity (including an independent advocate, who should be appointed at an early stage in the process by the RQIA in all such cases) to apply to have an Intervention Plan reviewed. The Tribunal may exercise its functions proportionately with regard to the methods by which it hears appeals, depending upon the seriousness of each individual case.

6.33 The RQIA and the Tribunal should work to common principles and in a complementary manner across the entire Framework. It is essential that within each of the two bodies the appropriate level and form of specialist expertise and training be provided and regulated, to ensure that they each retain at all times the levels of competency required for their respective functions to be carried out.

Promoting Autonomy and Safeguarding Interests

6.34 The Framework advocates the involvement of the individual in the decision-making process to the greatest extent possible, and endorses the use of both advance decisions and advance statements as a way of assisting the substitute decision-making process. The scope of each of these provisions should extend to decisions and interventions which relate to a person's mental disorder, as well as to any physical condition he/she may have. The former must be respected and considered equivalent to a person's contemporaneous refusal, and if they refer to life-sustaining interventions they must be in writing and witnessed. The latter must be taken into account as a valid expression of a person's wishes when his/her best interests are being decided. Any instance of an advance decision or advance statement being overruled must be reported to the RQIA.

6.35 The Framework also recognises the role that other people, including carers, can have in substitute decision-making (*cf.*, section 4 of the 2005 Act, which specifies that in determining *best interests* for a person with impaired capacity the views of, amongst others, "anyone engaged in caring for the person or interested in his welfare" should be taken into account). Where substitute decisions are to be taken, it is essential that, where appropriate, carers and/or advocates be kept informed of any decisions being made and of any processes open to them to challenge those decisions. However, it should be remembered that a person may be capable of refusing the involvement of a previous carer even if his/her judgement is impaired about other aspects of his/her management. In such situations, the appointment of some other appropriate *nominated person* should be facilitated.

6.36 The Framework provides for attorneys, independent advocates and Court-appointed deputies, all with roles very similar to those detailed in the 2005 Act. Thus, for example, individuals, including those who are users of mental health services, may appoint an attorney to make decisions on their behalf in the event of a subsequent impairment of capacity and such attorneys will have essentially the same authority with regard to specified decisions as if they were the persons with impaired decision-making capacity themselves. Independent advocates can be appointed when a person with impaired decision-making capacity has no other form of independent representation available – and they *must* be appointed when particularly serious issues (e.g. concerning deprivation of liberty or irreversible healthcare interventions) are involved. The appointment by the Court of a deputy solely for the purpose of making substitute-decisions on healthcare is only likely to arise where an agreed position among the various concerned parties is proving impossible to secure.

6.37 Where disputes arise amongst concerned parties, it is recommended that a mediation service be provided as a first response, certainly in cases thought capable of being settled through negotiation and in matters concerning essentially welfare (including financial) issues, with the Public Guardian as the next recourse. Likewise, the use of mediation and, if necessary, "second opinions" from appropriate specialists (not necessarily from the same profession as the original) could offer protection in contentious healthcare decisions. Ultimately, the Framework envisages access to the Court as a means of resolving disputes, with a subsequent right of appeal in particular cases. Such access should be facilitated by the provision of free legal aid.

Compulsory Assessment and Intervention

6.38 There have been substantial changes in policy and practice over the period since the 1986 Order became law. For example, the responsibility of GPs to provide a service to their patients out-of-hours has passed to Boards, and doctors working out-of-hours are less likely to have a direct knowledge of those persons who might require a compulsory assessment in relation to their decision-making capacity and the degree of risk they present to self or others. At the same time, the introduction of Crisis Response and Home Treatment Teams has resulted in nursing and other professionals becoming increasingly skilled at mental state and risk assessment.

6.39 The Framework envisages that, in addition to GPs, other appropriately trained clinicians (including nurses and clinical psychologists) – referred to as *Approved Clinicians* – could complete a recommendation for compulsory admission to an approved facility for assessment and ensure that the person's GP is informed and consulted as soon as possible. On arrival, the person will immediately be examined by a medical doctor and responsibility for his/her care and treatment will be transferred to a Responsible Clinician (see below, paragraph 6.40). It is envisaged that the separate and distinct role of the Approved Social Worker as applicant for compulsory assessment should continue.

6.40 The Framework recognises the substantial and further anticipated development of services since the introduction of the 1986 Order (for example, in the need for innovation in services for people with head injuries, eating disorders, personality disorder and learning disability with challenging behaviour, both in-patient and community-based, and not necessarily under medical direction or supervision). Given such development and the need to ensure that persons with impaired decision-making capacity who require either assessment and/or intervention on a compulsory basis have access to the most appropriate professional management, the Framework envisages that the role of the Responsible Medical Officer should, subject to appropriate training, approval and ongoing monitoring, be extended to professions other than psychiatry (such as clinical psychology) and re-named the *Responsible Clinician*. This will require clearly defined lines of professional accountability to ensure the continuous care of individuals during periods of detention, including protocols to ensure appropriate transfer of responsibility between clinicians involved in their care. The membership of Tribunals should also be extended to allow relevant non-medical clinicians to be included.

6.41 Persons for whom an assessment is to be carried out compulsorily must be seen by their Responsible Clinician at the start of the period of assessment, and regularly thereafter.

6.42 The Responsible Clinician will be responsible for co-ordinating and submitting Intervention Plans to the Trust for approval and to the RQIA for assurance (see above, paragraphs 6.20 and 6.30). The RQIA will be charged with confirming the legality of the process being adhered to, and will take such action as is appropriate in regard to this, including referral to the Tribunal if necessary. In addition, the RQIA will be responsible for assuring the quality of the content of proposed Intervention Plans. Panels may be constituted for this purpose, the membership of which should be drawn from a range of both lay and professional backgrounds, with each professional having an appropriate level of experience of either the type of mental disorder and/or the intervention proposed in relation to the case in hand. The RQIA may also request the assistance of an independent "second opinion specialist" in this process.

Research

6.43 Research is a particularly sensitive subject when a person's autonomy is compromised. Consideration should reflect the need to enhance properly conducted research to provide knowledge about the causes of incapacity and about diagnosis, treatment, care and the needs of people who lack capacity. Where research for such purposes can be carried out effectively only on persons whose decision-making capacity to consent is impaired, this should be permitted within the Framework, provided appropriate specified safeguards are assured. The Review recommends accepting the provisions and protections of the 2005 Act to allow such research to proceed (see above, paragraph 4.37). Safeguards should be designed so as not to discourage such research and hence deprive people of benefit. Users of services as well as carers should have a meaningful input into the research agenda. The RQIA should be specifically charged with the role of promoting such input.

Training and Awareness-Raising

6.44 Training (on a multi-disciplinary basis, where appropriate) and awareness-raising are essential if the new legislation envisaged by the Review is to be successfully introduced. Not only must it be ensured that those individuals and professionals who will be required to operate the Framework processes are competent to do so, but it must be ensured also that the general public, users of services and carers are kept fully informed at all stages of its introduction and operation, and that user and carer representatives participate in its development.

CHAPTER 7

A MODEL APPLICATION OF THE FRAMEWORK

Introduction

7.1 The essential components of a comprehensive Framework for substitute decision-making were presented in Chapter 6. In this Chapter, additional details are provided of how the Framework might operate in practice and of its possible impact on the lives of people with impaired decision-making capacity. This is done by way of a model application of the Framework ("the Model") which is summarised in the form of a flow diagram at the end of the Chapter. The Model is one example of a number of possible out-workings of the Framework.

Determination of Impaired Decision-Making Capacity

7.2 The Framework applies *only* to persons who have impaired decision-making capacity. Determining that a person has impaired decision-making capacity is a two-stage process: first, it must be demonstrated that he/she has "an impairment of, or a disturbance in the functioning of, the mind or brain"; and second, it must be demonstrated that it is because of that impairment or disability that the person is unable to make the decision at hand. The first component requires a determination that the person has some form of mental disorder (e.g. mental illness, learning disability, autistic disorder or acquired brain injury), while the latter should be determined through a similar procedure to that set out in section 3 of the 2005 Act but with the addition of an assessment of the person's *appreciation* of any information that is relevant to the decision to be made (see above, paragraphs 5.11 to 5.13).

7.3 A person may be determined at a particular point in time to have impaired decision-making capacity for a specific decision but then, perhaps because the effects of his/her mental disorder are temporary and/or fluctuating, he/she may be determined subsequently no longer to have such an impairment. Indeed this is often to be expected as an outcome of intervention. In order to decrease the likelihood of relapse, in cases where it can be anticipated that a person's decision-making capacity will change over time, provision should be made in a Code of Practice for both the nature of the person's illness or condition and any relevant historical information to be taken into account when assessing his/her decision-making capacity in relation to any proposed course of treatment which should be complied with over a period of time (see above, paragraph 5.19).

7.4 It is the individual who will be responsible for carrying out a proposed intervention who must ultimately be satisfied as to whether or not a person has impaired decision-making capacity, although it may at times be advisable to request an assessment by an appropriate specialist healthcare professional (usually a psychiatrist or a psychologist).

Substitute Decisions and Associated Interventions

7.5 The Model recognises three main types of decision and intervention, depending on the one hand on both their severity and the extent to which they intrude upon a person's autonomy, and on the other on the level of authority which is required before they can be carried out. These three categories are referred to respectively as *general interventions*, *formal interventions* and *specifically authorised interventions*.

7.6 All interventions proposed and undertaken by way of the Model, whether general, formal or specifically authorised, should comply with Good Practice Guidelines to be drawn up and overseen by the RQIA (see above, paragraph 6.31).

General Interventions

7.7 The great majority of decisions and interventions carried out on behalf of persons with impaired decision-making capacity will fall within the category of general interventions. These include a good many of those described as "acts in connection with care and treatment" in section 5 of the 2005 Act (and elaborated upon in that Act's Code of Practice), and range from such basic activities as the performance of personal, and sometimes intimate, care tasks (e.g. washing, dressing, feeding and personal hygiene tasks), through to routine and relatively benign activities such as shopping (e.g. for grocery items).

7.8 For any decision or intervention to be considered a general intervention within the Model, the following conditions must apply:

- the person either has, or is at least reasonably believed to have, impaired decision-making capacity (as detailed above, in paragraph 7.2);

- any proposed decision or intervention is in keeping with the Framework principles, in particular those of the person's best interests and the least restrictive alternative;

- the person has been supported and included within the decision-making process to the greatest extent possible, and does not disagree (nor is he/she considered likely to disagree in the future) with the action(s) proposed; and

- there is agreement amongst all concerned parties – including the person's carers, any advocate or attorney who may be involved and, if different, the individual(s) who will be responsible for carrying out the proposed decision or intervention – that:

    - the intervention constitutes neither a significant restriction upon, nor a deprivation of, the person's rights and liberty (cf., Article 5(1) of the ECHR);

    - neither do they constitute either a "prolonged or particularly serious intervention" (as defined below, in paragraphs 7.54 to 7.58, i.e. interventions which require a second specialist opinion, are expected to be prolonged or are likely to have irreversible consequences) or one of a very limited number of situations for which the Courts have previously directed that a Court declaration must *always* be sought (see below, paragraphs 7.16 and 7.59);

- the interventions proposed are likely to meet the specific needs of the person for care and protection; and, where appropriate,

- satisfactory care management procedures, including arrangements for monitoring and regular reviews, either are, or will be put, in place.

7.9 Provided *every* condition in this list is fulfilled, general interventions may be carried out under common law, with only minimal administrative constraints and with the persons who perform them having a measure of protection from legal liability for their actions.

7.10 However, if either the person with impaired decision-making capacity and/or any other concerned party (see above, paragraph 7.8) does not agree or otherwise objects to any proposed decision or intervention, or if it is adjudged that the scope of the intervention extends beyond that of a general intervention, it should be considered a formal intervention instead and the procedures and additional safeguards which are detailed in the following section should apply.

Formal Interventions

7.11 The defining feature of formal interventions is that they require and are subject to a prescribed administrative procedure which is regulated by a local Health and Social Care Trust – including appropriate provision for assessment, intervention, appeal and review in all cases.

7.12 Examples of the kinds of intervention which are likely to constitute a formal intervention within the Model include the following:

- healthcare interventions ranging from the relatively minor (e.g. routine dental treatment) to those that are significantly invasive and/or complex (such as admission to hospital for certain medical or surgical treatments);

- interventions undertaken on an emergency basis with the intention of saving a person's life (e.g. where the person is unconscious) or where there is an immediate risk of serious harm being caused to either the person him/herself or to some other individual(s) – such as when the person is behaving in a violent or dangerous manner (but see paragraph 7.14, below);

- low-level acts of restriction (as will be determined and specified by the RQIA in the Code of Practice – e.g. the use of arm-splints to prevent a person from injuring him/herself by striking his/her head); and

- where it is believed to be in the best interests of a person with impaired decision-making capacity to be placed within a hospital or a care home in circumstances where his/her liberty may be deprived, and for whom there are no objections to that proposed placement (*Bournewood*).

7.13 With two specific exceptions, formal interventions, just like general interventions, require that the entire list of conditions set out in paragraph 7.8 apply before any intervention can be implemented. The two exceptions are as follows:

- although the agreement of the person with impaired decision-making capacity is to be anticipated, it is recognised that this will not always be the case and, provided every other condition in the list is fulfilled, a formal intervention may still proceed – so long as it is considered by all other concerned parties to be both necessary and in the person's best interests – even in the absence of the person's agreement; and

- in the case of interventions carried out on an emergency basis, it is essential that only the first two of the list of conditions applies.

7.14 Although interventions carried out on an emergency basis will generally be deemed formal interventions within the Model (see above, paragraph 7.12), if any such intervention is considered likely to be repeated or continued over a period of time (i.e. beyond a specified period to be prescribed by the RQIA), it should be considered a specifically authorised intervention instead and the procedures and additional safeguards which are detailed in the following section should apply.

Specifically Authorised Interventions

7.15 Specifically authorised interventions are those which, because of their very high level of intrusiveness and/or complexity, require the imposition of a more robust procedural system and, proportionately, additional safeguards for those persons with impaired decision-making capacity on whose behalf they are carried out.

7.16 The Model recognises six specific types within three main categories of specifically authorised interventions:

(a) those which involve either:

(i) depriving a person with impaired decision-making capacity of his/her liberty (and where, unlike the *Bournewood* situation, the person either objects or otherwise does not agree to that deprivation); and/or

(ii) the use of any kind of significant restriction (which can be undertaken, as in the 2005 Act, only when such action is believed to be both *necessary* and *proportionate* to the degree of risk of harm to the person and/or others that is presented by his/her behaviour at the time – *cf*., section 6 of the 2005 Act);

(b) those which constitute a "prolonged or particularly serious intervention" – ie. those which:

(iii) require a second, specialist opinion;

(iv) are expected to last for a lengthy period; or

(v) are likely to have certain irreversible consequences, but which do not need to be performed on an emergency basis (neurosurgery, for example, or the administration of long-term medication for the relief of psychiatric symptoms); and

(c) those where:

(vi) it has previously been directed that all future such cases should be referred to the Court for a declaration – including the withholding or withdrawal of artificial nutrition and hydration, for example.

7.17 Specifically authorised interventions which fall within either of the first two of these categories ((i) to (v)) require a detailed, multi-disciplinary Intervention Plan to be submitted for initial approval to the Trust and for assurance to the RQIA, which will then be responsible for ongoing and regular review of same. Those which fall within the final category (vi) will continue to be referred to the Court.

Objections to Proposed Decisions and Interventions

7.18 Objections to general and formal interventions should be directed in the first instance to the Public Guardian and the appropriate Health and Social Care Trust respectively, while those against the content and the legality of Intervention Plans should be directed initially to the RQIA and the Tribunal respectively. If resolution cannot be achieved at those levels, however, it is possible for *any* case to which the Framework applies to be referred ultimately to the Court for a declaration.

Applicability of the Framework

7.19 As already indicated, the applicability of the Framework in particular instances depends on both (i) whether or not the person has impaired decision-making capacity and (ii) the level of risk (if any) involved. Throughout the remainder of this Chapter any reference to a person's *assessment* should be taken to mean an assessment of *each* of these factors.

7.20 In situations where it is unclear if a person has impaired decision-making capacity (see below, especially paragraphs 7.28 to 7.30), the higher and more immediate the risk appears to be (e.g. where a person presents as being at risk of imminent suicide), the greater the emphasis should be on the person's protection. Some time may be necessary for an assessment of the person's decision-making capacity to be undertaken – in an approved facility, if need be – during which, his or her "benefit" should be afforded precedence over any of the other Framework principles (see paragraphs 5.15 to 5.17).

Where Decision-Making Capacity is Not Impaired

7.21 Where a person is determined *not* to have impaired decision-making capacity, the Framework does not apply to that person and any decision that he/she makes, even if it appears to be unwise and even if, ultimately, it might bring about his/her death, must be respected (Dame Elizabeth Butler-Sloss, 2002).

7.22 This is the case irrespective of which (or both) of the two components of impaired decision-making capacity (see above, paragraph 7.2) the determination is founded upon. Thus someone who has a mental illness, for example, but whose decision-making capacity is not impaired (i.e. the person retains the capacity to make a decision for him/herself), may not be included within the Framework (but see paragraphs 7.23 and 7.24). It is the case also irrespective of whether a particular decision or intervention relates to a person's mental or physical health, and of whether his/her behaviour presents a risk to the safety of self and/or of others.

7.23 Individuals suffering from a mental disorder (or a suspected mental disorder, which requires assessment) and who have been assessed as retaining decision-making capacity, should be able to access an appropriate professional service for their care and treatment on a voluntary basis. Should they refuse services, however, and their behaviour is such as to place either themselves and/or others at risk, they must take responsibility for the consequences of any decisions they might make.

7.24 Any risk associated with a person with a mental disorder who presents a significant risk to others only – not to self – but who has been assessed as having decision-making capacity may need to be managed through alternative legislative provision within the Criminal Justice System (see above, paragraph 5.49).

Where Decision-Making Capacity is Impaired and There is No Significant Risk

7.25 If it is determined (or at least reasonably believed) that a person does have impaired decision-making capacity, and it is believed also that there is no significant risk involved to either the person or others, any decision and/or intervention that is proposed on behalf of that person may be undertaken – provided it is in his/her best interests, regard is paid to the least restrictive alternative, and the appropriate degree of authority/authorisation is secured.

Where Decision-Making Capacity is Impaired and There is Significant Risk

7.26 The Model envisages that a hierarchy of emergency powers to intervene in order to protect a person with (suspected) impaired decision-making capacity who may be vulnerable to neglect or ill-treatment will be developed, including a *duty to inquire* (*cf*., the MHCT Act 2003) placed on Trusts and warrants for entry to premises for a health and welfare examination and/or to remove a person to a place of safety.

7.27 Where a person has impaired decision-making capacity and there is believed to be "a significant risk to the health, safety or welfare of the person or the safety of others" – the same level of risk as applies in the MHCT Act 2003 – a period of assessment may be indicated. Depending on the risk involved, this may be either in the community, in the person's usual environment, or in an approved facility. It may also, depending on the circumstances, be either with or without the person's agreement (see below, paragraphs 7.32 to 7.40, for more on assessments.)

Where Decision-Making Capacity is Unclear

7.28 Where the status of a person's decision-making capacity is unclear and he/she agrees to an assessment being carried out, that assessment should take place in the least restrictive setting that is appropriate to his/her particular circumstances.

7.29 What may happen when a person's decision-making capacity is unclear but he/she does *not* agree to an assessment, depends upon the degree of risk involved. If there is "a significant risk of serious harm to self or others" (a higher level of risk than that specified above, in paragraph 7.27 – see paragraph 7.31, below) then the person may be assessed. Although it might be possible for this assessment to take place in a community setting, it is much more likely that, given the level of risk involved, it will occur in an approved facility and on a compulsory basis. (Again, see paragraphs 7.32 to 7.40 for details of assessments; see also paragraph 7.20 for the need for an increased emphasis on the person's protection in situations of uncertain decision-making capacity and both high and immediate risk.)

7.30 If a person requires an assessment but there is *not* "a significant risk of serious harm to self or others", then, unless he/she agrees to an assessment being carried out on a voluntary basis, no further action may be taken under the Framework (albeit paragraphs 7.23 and 7.24, above, may still apply) and the person must take the consequences of any decisions he/she might make.

Assessments and Assessment Outcomes

7.31 The Model distinguishes between two separate levels of risk as the bases on which an assessment may be authorised compulsorily, if necessary: "a significant risk to the health, safety or welfare of the person, or the safety of others" (paragraph 7.27) and "a significant risk of serious harm to self or others" (paragraph 7.29). The former, lower level is intended primarily to facilitate the protection of individuals who are already known to have a condition which impairs decision-making capacity, while the latter, higher level seeks to restrict those instances where a person's lack of agreement to an assessment can be overruled to the highest levels of risk only.

Assessments

7.32 The preferred location for assessments undertaken as part of the Framework is the person's usual environment. However, the actual setting will depend on both the immediacy, nature and degree of any risk that is presented, and on whether the person offers any objection. The least restrictive approach should be adopted, and if it can be made safe for the person to remain in his/her usual environment, the assessment should be carried out there – with, for example, the authorisation for such assessment requiring that the person (and/or his/her carers) facilitate access by specified professionals and/or attend at specified locations.

7.33 It is anticipated that the majority of assessments will be carried out in the community, under *formal authority* (i.e. in accordance with a prescribed administrative procedure which is regulated by a local Health and Social Care Trust – see above, paragraph 7.11). This will certainly be the case where there is little or no risk involved and where the person offers no objection.

7.34 However, if it is not possible for an assessment to proceed in the person's usual environment – perhaps because of a failure on the part of the person to agree, or because of significant risks to either the person and/or others associated with his/her remaining there – consideration should be given to whether the risks presented by the situation require the assessment to be carried out in an approved facility instead.

7.35 Provided the person raises no objections, some assessments carried out in an approved facility might also proceed on the basis of formal authority only.

7.36 However, where there is a significant level of risk involved and/or the person objects to an assessment being carried out, *specific authorisation* will be necessary (*cf.*, paragraph 7.15). This will involve the submission of an *Interim* Intervention Plan, in a format similar to that of a (full) Intervention Plan (see paragraph 6.21), to the Trust and to the RQIA.

7.37 In practice, if there exists a "significant risk to the health, safety or welfare of the person, or the safety of others", he/she should be referred immediately for assessment to a community-based, multi-disciplinary mental health or learning disability team which is resourced to provide such a service (*cf.*, the Review's Strategic Framework for Adult Mental Health Services Report). If the person is unwilling to allow an assessment to take place, however, then proportionate action may need to be taken to ensure that he/she has access to appropriate care and treatment, and an assessment should be authorised through an application for same by the appropriate health and social care professional(s).

7.38 Whenever authorisation is given for a person to undergo a compulsory assessment – irrespective both of the level of risk on which the authorisation is granted and of the location of the assessment – this should be for a maximum of 21 days rather than the 14 days currently allowed within the 1986 Order for compulsory assessment. This longer period is to facilitate the enquiries, investigations and consultation that are needed and, where appropriate, the development of a multi-disciplinary Intervention Plan. The protection currently offered by Article 10 of the 1986 Order, for the disregarding of periods of assessment for certain legal purposes if the person is not detained thereafter for treatment/intervention, should be extended accordingly.

7.39 During the assessment period, if the person has no alternative form of independent representation available, an independent advocate (with responsibilities and duties similar to those detailed in sections 35 to 41 of the 2005 Act with regard to what are there called *independent mental capacity advocates*) should be engaged at as early a stage as possible to assist the person's understanding of the legal procedures involved – including his/her rights to appeal during the assessment process – and also to ensure that the person's own views are as fully articulated and communicated as possible to those who will be responsible for carrying out any proposed interventions.

7.40 Responsibility for determining the level of security required for persons admitted for a period of assessment (and, if appropriate, subsequent intervention) from the Criminal Justice System should remain with the Criminal Justice System throughout the time that the person remains engaged with the Framework processes.

Assessment Outcomes

7.41 There are essentially two possible outcomes to a period of compulsory assessment. The first applies if at any time throughout the assessment it is determined either that the person does *not* have impaired decision-making capacity and/or that the "risk" grounds on which the assessment had originally been authorised do not (or no longer) apply: once either of these becomes evident, the person should be discharged forthwith. (Alternatively, of course, the person may agree instead to be treated voluntarily, at any time either during or at the end of the assessment period.)

7.42 The second possible assessment outcome assumes that by the end of the assessment period it has been determined not only that the person *does* have impaired decision-making capacity, but also that the respective "risk" grounds on which the assessment had originally been authorised do apply. Here, if any intervention that requires specific authorisation is then proposed, the person's Responsible Clinician must submit an Intervention Plan to the Trust for approval and to the RQIA for assurance before the end of the proposed 21-day assessment period. (The subject and operation of Intervention Plans will be returned to below, at paragraph 7.46.) Otherwise, once the assessment is ended, the person will remain subject to the Framework processes on exactly the same basis as anyone else, and general and/or formal interventions may be applied (with the usual safeguards – see paragraphs 7.7 to 7.10 and 7.11 to 7.14 respectively) as appropriate.

Interventions Involving Low-Level Restriction and/or Deprivation of Liberty

7.43 The Framework recognises that care must be exercised in the regulation of restrictive practices in general, and restraint in particular. The RQIA will be responsible for regulating, and for preparing and disseminating guidelines for the safe and effective usage of, restrictive interventions.

7.44 The distinction between *deprivation* of and *restriction upon* a person's liberty is essentially quantitative, i.e. one of degree. Deprivation is where "complete and effective control" is exercised over a person's care and movements, including where a person is required to reside in a specific facility in order to receive treatment for his/her mental disorder (*cf.*, the *Bournewood* case). Restrictive interventions include a variety of forms of restraint – whether physical, mechanical, or chemical (i.e. through the use of medication) – or specifying particular individuals with whom a person with impaired decision-making capacity should not live or associate.

7.45 Relatively low-level restrictions (to be determined by the RQIA), plus cases of *Bournewood* deprivation (i.e. where a non-objecting person with impaired decision-making capacity is moved into a hospital or care home), are each considered *formal interventions* within the Model (see above, paragraphs 7.11 and 7.12). Thus they may be undertaken only in accordance with procedures drawn up and regulated by, and under the authority of, a local Health and Social Care Trust. They must also be regularly reviewed by that Trust. In Bournewood cases, such reviews must be carried out at least annually, even when there are no objections, and any objections which do arise and which cannot be resolved at Trust level may be referred to a Court for resolution.

Specifically Authorised Interventions Requiring an Intervention Plan

7.46 The vast majority of *specifically authorised interventions* (i.e. all those which do not as a result of a previous Court direction require a Court declaration) will need a multi-disciplinary Intervention Plan to be drawn up and submitted for approval by the Trust and assurance by the RQIA. The minimum content expected of an Intervention Plan was presented above, in paragraph 6.21, and, for ease of reference, is reproduced here:

- a declaration from the Responsible Clinician that:
  - the person's capacity to make a decision for him/herself is impaired because of "an impairment of, or a disturbance in the functioning of, the mind or brain" (and with the most likely reason(s) for such impairment being clearly indicated);
  - any proposed decision or intervention has been exposed to a rigorous application of the Framework principles, in particular those of the person's best interests and the least restrictive alternative;
  - the proposed intervention is available and is likely either to prevent the person's condition from worsening, or to alleviate its symptoms or effects;
  - if the proposed intervention was not to be provided, there would be a significant risk to either (i) the health, safety or welfare of the person or the safety of others or (ii) the person and/or others of serious harm (as appropriate – see paragraph 7.31); and
  - the intervention could not be provided without the authorisation of the proposed Intervention Plan;
- full details of the person's assessed needs and the nature of the proposed intervention (which will generally be in the form of a multi-disciplinary care plan), including any elements of significant restriction and/or deprivation of liberty;
- details of the setting in which the intervention is to be carried out (i.e. in a community setting or an approved facility); and

- details of the rights of the person (and/or of his/her representative) to appeal against the Intervention Plan.

7.47 The precise content of an Intervention Plan will depend upon the individual circumstances, although any compulsory elements must always be detailed. So too must any components which are considered essential, since it is anticipated that there will be a responsibility on service-providers for these to be provided.

7.48 These apart, the content of an Intervention Plan will depend upon whether or not it is intended to include any measures that could be deemed to constitute (i) either a significant restriction upon, or a deprivation of, the person's liberty, or (ii) a prolonged or particularly serious intervention. These are dealt with respectively in the following two sections, wherein further details about Intervention Plans will be presented as appropriate.

Interventions Involving Significant Restriction and/or Deprivation of Liberty

7.49 Interventions involving relatively low-level restrictions and/or cases of *Bournewood* deprivation (i.e. where a non-objecting person with impaired decision-making capacity is moved into a hospital or care home), were considered above, in paragraphs 7.43 to 7.45. They are each considered *formal interventions* within the Model.

7.50 More significant restrictions (again, as will be determined by the RQIA), as well as cases of deprivation in which there is not agreement, constitute *specifically authorised interventions* within the Model. As with all interventions, these may only be undertaken if they are in the best interests of the person with impaired decision-making capacity. Additionally, and in accordance with section 6 of the 2005 Act, they must also be both *necessary* and *proportionate*. However, whereas the 2005 Act sanctions the use of such interventions in relation to the likelihood of harm occurring to a person with impaired decision-making capacity only, the Model extends that authorisation to cases of *other* people being placed at risk by the person's behaviour as well – e.g. a person with paranoid delusional beliefs, the subject(s) of whose beliefs may be at serious risk of harm, whether physical or psychological. (This is in line with the underlying principle of Benefit, since it cannot ultimately be of benefit to a person for his/her behaviour to be allowed to place other individuals at risk – not least because, by so doing, he/she may face a period of incarceration.)

7.51 All interventions which include either deprivation and/or significant restrictions on a person's liberty must be specified within an Intervention Plan, to be drawn up by the person's Responsible Clinician and to include, as a minimum, the information detailed above, in paragraph 7.46.

7.52 The Intervention Plan should be submitted to the Trust for approval and for assurance to the RQIA initially, on each occasion it is amended significantly (as defined in a Code of Practice) and at least annually thereafter. This may require the establishment of a panel comprising a range of both professional expertise and service user- and carer-representation, to approve both the process and the content of the proposed Intervention

Plan. In addition, for interventions amounting to a deprivation of liberty, the Intervention Plan should be referred to the RQIA after an initial 21 days and should be reviewed by the RQIA at 6-monthly intervals thereafter, rather than yearly.

7.53 If the person has no other form of independent representation, an independent advocate must be appointed on his/her behalf in cases where a significantly restrictive intervention is proposed, and either the person, the independent advocate and/or the RQIA should be able to refer such a decision or intervention to the Tribunal from the beginning of the assessment process. For interventions amounting to a deprivation of liberty, an independent advocate must be appointed on behalf of the person in any event, i.e. even if he/she already has an alternative form of independent representation. As an additional safeguard, the Tribunal will review each Intervention Plan after its initial 3 months, in a proportionate manner.

Prolonged or Particularly Serious Interventions

7.54 In recognition of the fact that the most serious and prolonged interventions should carry with them the most robust forms of protection for persons with impaired decision-making capacity, the Model identifies three specific categories of such. These have all been described above, in paragraph 7.16:

- interventions requiring a second specialist opinion, including situations where:
  - the person with impaired decision-making capacity either objects to, or does not agree to, a major invasive intervention;
  - there is no agreement on what constitutes the person's best interests (e.g. due to different views amongst relevant parties, a significant possibility that the adverse effects of the proposed intervention may outweigh its benefits, or where a potentially life-sustaining intervention is subject to dispute);
  - the proposed intervention falls outside the scope of recognised clinical guidelines; or
  - a specific regulated intervention, such as ECT, is proposed;
- certain prolonged interventions; and
- procedures with irreversible consequences.

7.55 As with all decisions and interventions carried out on behalf of persons with impaired decision-making capacity, any prolonged or particularly serious intervention must be adjudged to be in the person's best interests, and regard must be had of the least restrictive alternative. In addition to providing details about the proposed intervention itself, any resulting Intervention Plan should include a declaration in respect of each of the areas specified above, in paragraph 7.46.

7.56 In the case of interventions which require a second opinion, one appropriate specialist approved by the RQIA and not otherwise involved in the case must concur with the Intervention Plan, while two such independent and appropriate specialists must concur with Plans involving interventions which have irreversible consequences.

7.57 Intervention Plans in respect of prolonged and particularly serious interventions should be submitted to the Trust for approval and to the RQIA for assurance, each time they are amended (if indeed they are amended), and thereafter at least every 6 months (for second opinion cases) or annually (for prolonged interventions).

7.58 Also, as with Intervention Plans specifying deprivation of liberty (see paragraphs 7.52 and 7.53), for those which specify prolonged or particularly serious interventions an independent advocate must be appointed on behalf of the person, even if he/she already has an alternative form of independent representation. Also, either the person him/herself, the independent advocate and/or the RQIA may refer such a decision or intervention to the Tribunal, which will review the Intervention Plan after its initial 3 months.

Interventions Requiring a Court Declaration

7.59 The Courts have previously directed that there exist a (limited) number of situations (e.g. non-therapeutic sterilisation) wherein only the Court should be able to authorise a particular intervention (see above, paragraph 7.16). The Model contemplates that all such cases will continue to be referred to the Court for a declaration.

Persons Involved in Criminal Proceedings

7.60 The Framework should support the principle of equivalence, that those who are subject to the Criminal Justice System should have access to treatment and care that is equivalent to that available to other members of our society. Thus service users should be facilitated to access appropriate services primarily on a voluntary basis and with a minimum of restriction, commensurate with public safety. Arrangements in the Framework for people who are subject to the Criminal Justice System, such as assessment of decision-making capacity and the implementation of Intervention Plans should, as far as possible, be equivalent to those applicable to everyone else. The timescales that apply to these provisions should generally be the same as apply outside the Criminal Justice System and the safeguards for those with impaired decision-making capacity must be at least as robust. The provisions of the Framework should facilitate and promote detailed assessment of individuals so that decisions affecting their future can be made by the relevant bodies after consideration of all the necessary information.

Transfer of Prisoners to Approved Facilities for Assessment, Treatment and Care on a Voluntary Basis

7.61 At present, prisoners who suffer from physical health problems that warrant inpatient treatment in hospital are generally admitted to hospital to receive the treatment they require, while retaining their status as prisoners and remaining subject to the requirements of the

Criminal Justice System. Equivalent high quality treatment should be available to prisoners who suffer from mental health problems. There is no system in routine use in Northern Ireland whereby a prisoner who is suffering from a mental health or learning disability problem that warrants treatment in hospital and who has decision-making capacity and gives his or her consent may be transferred to hospital to receive assessment, treatment and care on a voluntary basis. Measures should be introduced to allow the transfer of such prisoners to an appropriate facility (usually a hospital) so that they can receive care on a voluntary basis rather than being subject to compulsory powers of treatment. Such individuals would retain their status as prisoners and thus be subject to the requirements of the Criminal Justice System.

Assessment Orders and Intervention Orders

7.62 Under the proposed new legislation the Magistrates Courts, Crown Courts and, additionally, the Court of Appeal should be given powers to authorise the assessment of an individual's decision-making capacity and associated risks, and this may require admission to an approved facility (usually a hospital). This process of remand for assessment should be similar to admission for assessment for people in the community. Where appropriate, this may be followed by an Intervention Order to enable further compulsory treatment and care. When the Court remands an individual to hospital for assessment or treatment it should indicate whether the Responsible Clinician may give the person temporary leave from hospital or whether the decision to grant leave is to be reserved to the Court. Once an individual no longer requires assessment or treatment the new legislation should facilitate his or her prompt return to Court for alternative disposal.

7.63 New legislation should contain provisions to enable Courts to make compulsory Intervention Orders (similar to the current Hospital Order, Interim Hospital Order and Guardianship Order). It is important that people are assessed in detail before such disposals are made and a Court should record its reasons if it makes an Intervention Order without first making an Assessment Order or Interim Intervention Order.

7.64 When an individual is to be made subject to the powers of the new legislation, those who are making an application or recommendation must have seen the individual within a specified period of time. The same timescales should apply whether or not the individual is involved in criminal proceedings.

7.65 In the case of acquitted persons with recommendations for assessment, these recommendations should provide sufficient authority to permit the individual to be assessed in an appropriate location.

Intervention Orders Combined with Other Sentences

7.66 In Scotland, Hospital Directions have been introduced which allow a Court to impose a sentence of imprisonment, including a life sentence for murder, and at the same time to authorise that the convicted person is admitted to and detained in hospital. Similar disposals have also been introduced in England and Wales. Hospital Directions are considered particularly appropriate in certain cases, for example where there is not considered to be a strong association between the offender's mental disorder and the offence, or the alleviation of those aspects of the person's mental state which are likely to respond to treatment may not substantially reduce the extent to which the offender presents a risk to the public.

7.67 The Review recommends that it should be possible for the Court to combine an Intervention Order with certain other specified sentences such as a prison sentence or a Custody Probation Order. When making such a disposal the Court should state the options it has considered and the reasons for its decision. Appropriate appeal mechanisms are required to enable the individual to appeal against the Intervention Order component of the disposal.

Restriction Orders

7.68 Under the provisions of the 1986 Order, a Restriction Order may be superimposed on Hospital Orders or Transfer Direction Orders in certain cases where an individual is suffering from mental illness or severe mental impairment and it appears that it is necessary for the protection of the public from serious harm. No comparable disposal is available to the Courts in situations where an individual is not suffering from such a mental condition yet poses a similar risk of serious harm to the public. While the Review recognises the importance of measures designed to protect the public from serious harm it is concerned that Restriction Orders may unjustifiably discriminate against people suffering from certain types of mental disorder.

7.69 Currently, the Secretary of State is authorised to make decisions about people who are subject to Restriction Orders, such as whether to grant the individual leave from hospital, to transfer him to another hospital, to discharge him from hospital or to recall him to hospital. It has been suggested (cf., both the Richardson Report and the Millan Report) that such decisions should be taken by a body that is manifestly independent of political influence. It would seem appropriate for the new legislative framework to incorporate future measures in relation to the risks posed by people suffering from mental disorder within a wider and independent risk management framework that addresses the full range of people who pose a risk of serious harm to the public.

Transfer Between Prison and Approved Facilities

7.70 The 1986 Order contains provisions to enable the Secretary of State to direct the transfer of prisoners to hospital for treatment but not for assessment of their mental condition. The Framework should include provisions for the relevant authority to transfer prisoners to approved facilities (usually hospital) for assessment, followed, if appropriate, by submission and approval of Intervention Plans. Transfers between prison and approved facilities should occur within the same timescales as experienced by service users in the community.

Arrangements for Transferred Prisoners on Expiry of Sentence

7.71 Where a person subject to an Assessment Order or an Intervention Order would be entitled to be released from prison, but it is considered that the prisoner requires continued detention under the legislation, it should be necessary for the continued detention to be referred to the Tribunal (or to have the right of appeal to a Tribunal) and the individual should be treated as if subject to normal civil procedures.

Appeals Against Excessive Restriction in Hospital

7.72 The principle of treating people under conditions of security no greater than is justified by the degree of danger they present to themselves or others is strongly supported. In Scotland, the MHCT Act 2003 includes measures to enable appeal against detention in excessively restrictive circumstances. It is proposed that similar measures, informed by the Scottish experience, should be introduced in Northern Ireland.

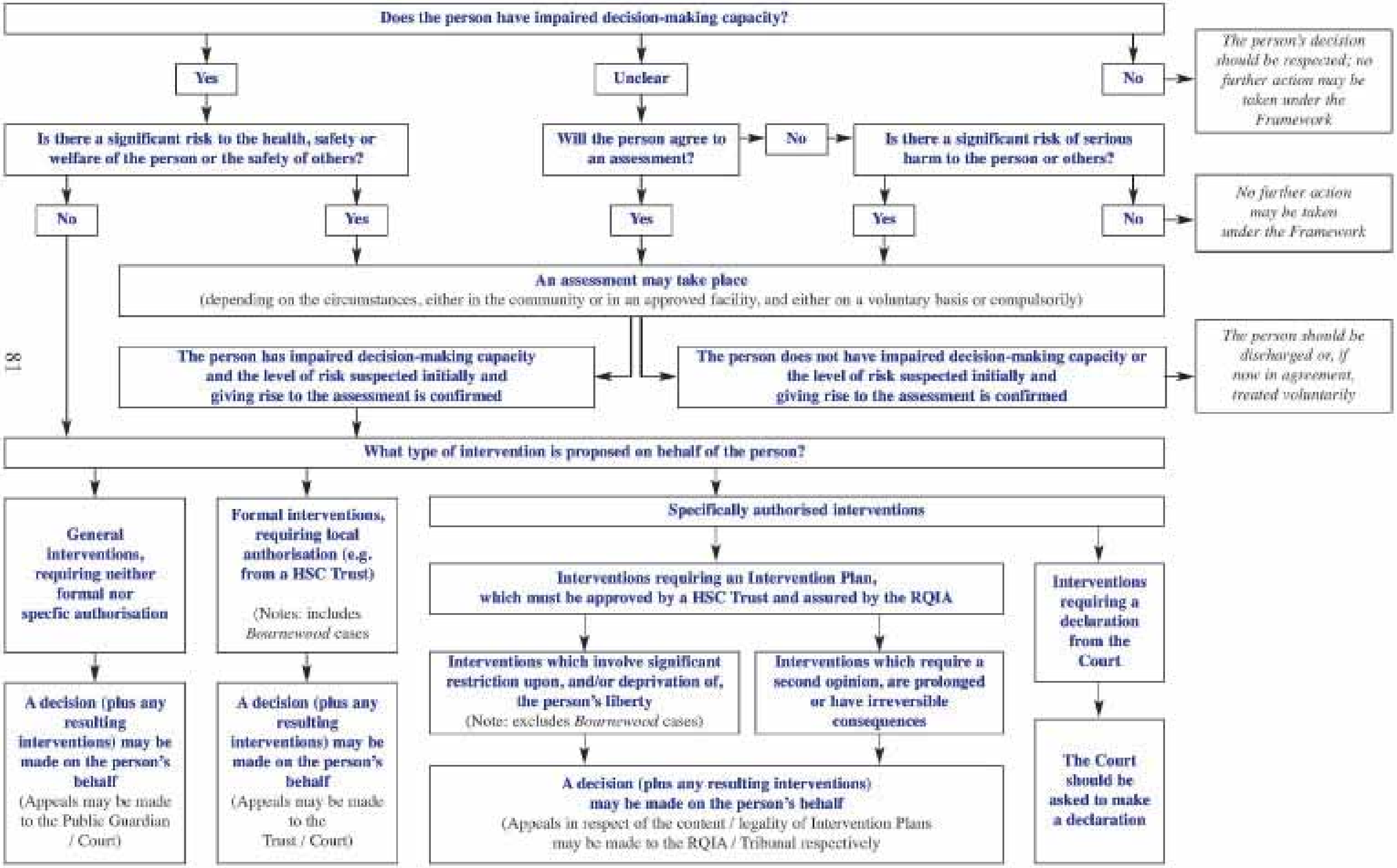
Patients Removed To and From Northern Ireland

7.73 Currently, people who are remanded to prison and who are suffering from mental disorder that warrants transfer to a high security facility cannot be transferred to a hospital outside Northern Ireland. There is no maximum security facility in Northern Ireland and thus these individuals are denied the opportunity of assessment and treatment. Mechanisms must be found to enable urgent access to treatment in high security facilities when necessary and these may require additional legislative change.

7.74 Arrangements should also facilitate transfers between other jurisdictions, including in emergencies and for short periods, for example to facilitate visits or rehabilitation programmes.

Flow Diagram Summarising Action in Cases of (Suspected) Impaired Decision-Making Capacity where a Decision Must Be Made and there is No Attorney or Valid Advance Statement

(Notes: Any decision taken must (i) be in the person's best interests and (ii) take account of the least restrictive alternative; the person should have access to advocacy at all levels of the diagram)



CHAPTER 8

RECOMMENDATIONS AND WAY FORWARD

The Journey So Far

8.1 The Review's detailed consideration of the need for reform of Mental Health legislation has persuaded us that the time is right for a principles-based approach to legislative provision for our community. At its heart is the need for regard for human dignity and for the human rights of every citizen. This approach has led us to propose a new legislative Framework based on explicit principles.

8.2 As noted earlier, the expression of these Framework proposals is not an attempt at legislative drafting but an explanation of what we believe is necessary for reforming current legislation, applying a principles-based approach. Many of the proposals involve new considerations for legal provision in health and social care practice, for example a capacity approach to mental health provision, advance statements about treatment and treatment in the least restrictive setting. The details presented in the Model have been provided to show how such a Framework might work in practice and as an aid to illustrate those issues which will need further research, development and consultation.

8.3 Extensive and wide-ranging discussion over the last 4 years, together with consultation both within the Review and with several external experts, along with stakeholder contributions have all contributed to the development of the present Framework proposals. There has been general support for the approach taken and for the proposals and recommendations.

Next Steps

8.4 The inter-departmental approach to the process of implementing the Bamford Review reports will be central to the successful development of legislative reform, which must be given a high priority by Government. It will be essential to have co-ordination between DHSSPS and other Departments, for example on risk management, on the particular needs of children and young people and on the need for a joint approach to effective monitoring and evaluation of the agreed framework. Given the day-to-day reality of individual mobility between the countries of the United Kingdom and the Republic of Ireland, consideration must be given to the inter-jurisdictional compatibility and utility of legislative provision.

8.5 The Review considers that the successful introduction of new legislation will depend critically on the effective implementation of the recommendations of all the reports of the Bamford Review on policy and services. Indeed, consideration must be given to a phased introduction of aspects of legislation in tandem with appropriate service development.

8.6 In order to ensure that legislative change translates into meaningful improvements in the lives of those it is there to support, it is essential that there is a well-resourced strategy for the education and training needs of all those individuals likely to be involved in the application of legislative provision, including the simultaneous introduction of a Code or Codes of Practice. An information programme for the general public, service users, carers and professionals must be provided.

Recommendations

8.7 The Review, therefore, makes the following recommendations which will establish the basis of, and set the direction for, change in legislation.

Overarching Recommendations

1. There should be a single, comprehensive legislative framework for the reform of Mental Health legislation and for the introduction of Capacity legislation in Northern Ireland. This should be through the introduction of provisions for all persons who require substitute decision-making. A framework is proposed for interventions in all aspects of the needs of persons who require substitute decision-making, including mental health, physical health, welfare or financial needs.

2. The framework should be based on agreed principles, explicitly stated in legislation and supplemented, if necessary, in supporting Codes of Practice.

3. The principles underpinning new legislation should support the dignity of the person and have regard to:

Autonomy: respecting the person's capacity to decide and act on his own and his right not to be subject to restraint by others.

- There should be an assumption of capacity and provision of care and treatment should be on a partnership and consensual basis, as far as possible. Respect for capacitous decisions should extend to those decisions made legally in advance and where the person grants specific decision-making powers to another on his behalf, for the time when he loses capacity himself.
- Participation - users of services should be fully involved to the extent permitted by the person's capacity, in all aspects of their care, support or treatment. Users of services should be provided with all the information and support necessary to enable them to participate. This may include the involvement of advocates and/or carers. Account should be taken of past and present wishes in so far as these may be ascertained.

Justice: applying the law fairly and equally.

- Non-discrimination - persons with a mental disorder or a learning disability should retain the same rights and entitlements as other members of society.
- Equality and respect for diversity - persons should receive treatment, care

and support in a way that accords respect for, and is sensitive to their individual abilities, qualities and cultural backgrounds. The legislation should not discriminate on grounds of age, gender, sexual orientation, ethnic group, disability, social class, culture or religion.

- Reciprocity - the loss of a person's rights by detention or by compulsion to treatment and care should be matched by an obligation to provide adequate treatment and care for that person.
- Partnership - services should develop effective partnerships to ensure continuity of care across age and service boundaries.
- Fairness and transparency - there should be fairness and transparency in decision-making, and the right to representation for challenge of due process. Proceedings should be timely.
- The specific rights of children, including the right to education, should be protected.

Benefit: promoting the health, welfare and safety of the person, while having regard to the safety of others.

- Where interference is necessary and permissible, the best interests of the person should be protected and promoted, including protection from abuse and exploitation.
- Interventions should only be undertaken using the legislation to achieve benefits which cannot be achieved otherwise. Benefit to the person should include, but not be limited to, reduction of risk of harm to self or others.

Least Harm: acting in a way that minimises the likelihood of harm to the person.

- The person should be provided with the necessary care, treatment and support in the least invasive manner and in the least restrictive environment compatible with the delivery of safe and effective care. The perception of the restriction by the person himself should be taken into account.
- There should be clear guidance on the use of restrictive practices such as restraint, seclusion and time out for both adults and children, and these should be monitored and subject to evaluative research.
- There should be clear guidance on how and when research may be carried out with persons who have impaired decision-making capacity and this should be monitored.

4. These principles should apply in a non-discriminatory and balanced way to all healthcare decisions, as well as to welfare and financial needs.

5. Grounds for interfering with a person's autonomy should be based on his or her impaired decision-making capacity.

6. The definition used in the Mental Capacity Act 2005 should be adopted in Northern Ireland, specifically that:

   "a person lacks capacity if in relation to a matter at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain. It does not matter whether the impairment or disturbance is permanent or temporary."

   Impairment of, or disturbance in the functioning of, the mind or brain includes mental disorder, as defined in the Mental Health (Northern Ireland) Order 1986, which subsumes "mental illness, mental handicap and any other disorder or disability of mind". It includes disorders due to injury or disease such as stroke. The test of capacity should include all those aspects of mental functioning which affect decision-making capacity (not just cognitive impairment).

7. Children and young people under the age of 18 who are affected by the proposed approach to substitute decision-making should be afforded special protections.

8. A comprehensive legislative framework must take account of the particular needs and protections necessary for vulnerable adults, including those compliant persons with impaired decision-making capacity who are deprived of their liberty ("Bournewood" situations).

9. Persons who are subject to the Criminal Justice System should have access to assessment, treatment and care which is equivalent to that available to all other people.

10. Legislation must provide appropriate public and individual protection to the community against harm from persons whose decision-making capacity is impaired and who present a risk to others. On the other hand, legislation must not discriminate unjustifiably against persons who suffer from a mental health problem or learning disability.

Specific Recommendations

11. Specific key provisions of the Mental Capacity Act 2005 should be introduced for the proposed legislative Framework, with minimal amendment. These include:

    - the definitions of decision-making capacity and persons with impaired decision-making capacity;
    - a requirement that any decision or action undertaken on behalf of a person with impaired decision-making capacity must be in his/her best interests and must have regard for the least restrictive option available;

- legal protection for the performance of everyday acts carried out in connection with a person's care or treatment;
- provision for attorneys, acting under Lasting Powers of Attorney (LPAs), to deal with welfare (including healthcare) in addition to property and finance;
- an enlarged jurisdiction of the Court in relation to welfare, healthcare and financial matters;
- powers of the Court to make declarations and orders and to appoint deputies;
- the recognition of advance decisions to refuse treatment and, in addition, advance statements about preferred treatment;
- safeguards in relation to research involving persons with impaired decision-making capacity;
- independent advocates;
- Codes of Practice;
- a new offence of ill-treatment or neglect;
- the appointment of a Public Guardian; and
- ratification of the Convention on the International Protection of Adults.

12. The following provisions, which are not within the Mental Capacity Act 2005, although some of which are currently defined in Mental Health law, should be included within the proposed legislative Framework:

- compulsory admission to an approved facility for assessment;
- compulsory detention in hospital for treatment;
- supervised intervention in the community;
- a system for the management of risk
- provision for prolonged and particularly serious interventions;
- an enhancement of the role and functions of the Mental Health Commission, which will transfer to the Regulation and Quality Improvement Authority;
- a development of the role and functions of the Mental Health Review Tribunal;

- the introduction of a nominated person as a replacement for the "nearest relative", with a re-definition of the corresponding role;
- an enhancement of the role and recognition of the rights of carers (such as family or friends);
- an extension of certain professional boundaries and functions, with the creation of two new professional posts, the Approved Clinician and the Responsible Clinician; and
- ratification of the Convention on the Rights of Persons with Disabilities.

Recommendations on Implementation

13. The proposed application of a capacity approach to interventions should be the focus for early local evaluation. The training needs and practicalities surrounding capacity assessment in clinical and other settings should be evaluated in advance of any proposed introduction of legislation.

14. The general public, users of services and carers must be kept fully informed at all stages of the introduction and operation of new legislation.

15. Training programmes on the proposed new legislation are essential for those persons who will be required to operate it and for users of services and their carers. The legislation, Codes of Practice and related training programmes must be introduced together.

16. Adequate resources must be made available to operate the procedures and bodies prescribed by the new legislation.

17. The Criminal Justice System should take the lead in developing an inter-agency risk assessment and management approach. This should co-ordinate with the proposed legislative framework. It should apply to all offenders who pose a prescribed level of risk, irrespective of whether or not these persons suffer from a mental health problem or learning disability.

18. The proposed comprehensive legislative framework should be taken forward through a joint initiative involving the DHSSPS, the Civil Law Reform Division of the Department of Finance and Personnel, the Northern Ireland Court Service and the Northern Ireland Office. This group should be responsible for translating the proposals into new provision for Northern Ireland. Users of services and carer representatives must participate in the development of the legislative framework.

Annex 1

TERMS OF REFERENCE FOR THE BAMFORD REVIEW

1. To carry out an independent review of the effectiveness of current policy and service provision relating to mental health and learning disability, and of the Mental Health (Northern Ireland) Order 1986.

2. To take into account:

   - the need to recognise, preserve, promote and enhance the personal dignity of people with mental health needs or a learning disability and their carers;
   - the need to promote positive mental health in society;
   - relevant legislative and other requirements, particularly relating to human rights, discrimination and equality of opportunity;
   - evidence – based best practice developments in assessment, treatment and care regionally, nationally and internationally;
   - the need for comprehensive assessment, treatment and care for people with a mental health need or a learning disability who have offended or are at risk of offending; and
   - issues relating to incapacity.

3. To make recommendations regarding future policy, strategy, service priorities and legislation, to reflect the needs of users and carers.

Annex 2

MEMBERSHIP OF THE LEGAL ISSUES WORKING COMMITTEE AND ITS SUB-GROUPS

LEGAL ISSUES WORKING COMMITTEE

Convenor:	Master Brian Hall	Master, Office of Care and Protection
•	Prof David Bamford*	Chair of the Review
•	Mrs Angela Bell	Criminal Justice Division, NIO
•	Dr Fred Browne	Consultant Forensic Psychiatrist, Shannon Clinic
•	Miss Marie Crossin	Chief Executive, CAUSE
•	Mr John James	User Representative
•	Mr Mervyn Morrow QC	Deputy Chair, Mental Health Review Tribunal
•	Mr Winston McCartney*	User Representative
•	Dr Mary McClean	Carer Representative
•	Prof Roy McClelland	Chair of the Review
•	Dr Maria McGinnity	Consultant Psychiatrist, Muckamore Abbey Hospital
•	Prof Tony McGleenan	University of Ulster/Bar Library
•	Mr Noel McKenna	Carer Representative
•	Mrs Mary O'Boyle	Assistant Director, Mental Health, Holywell Hospital
•	Ms Kitty O'Kane	User Representative
•	Mrs Anne Rafferty	Criminal Justice Division, NIO
•	Mr Alastair Rankin	Solicitor
•	Miss Brenda Ross	Criminal Justice Division, NIO
•	Dr Oliver Shanks	Consultant Psychiatrist
•	Master Hilary Wells	Master, Office of Care and Protection

* During the work of the Review Mr Winston McCartney and Professor David Bamford sadly died. Professor Roy McClelland (who had been acting as Deputy Chair) succeeded Professor Bamford as Chair of the Review.

SUB-GROUP 1 - which considered Definitions and Terminology, Personality Disorder and the needs of Children and of People with Learning Disability

Membership:

Convenor:	Dr Maria McGinnity	Consultant Psychiatrist, Muckamore Abbey Hospital
•	Dr Ivan Bankhead	Consultant Clinical Psychologist, Homefirst Trust
•	Mrs Christine Bateson	Crisis Response Team, Homefirst Trust
•	Mr Maurice Devine	Consultant Nurse in Learning Disability
•	Dr Aine Downey	Lay Member, Mental Health Review Tribunal
•	Dr Ruth Elliott	Consultant Clinical Psychologist
•	Mrs Anne Fenton	Director of Professional Legal Studies, QUB
•	Dr Peter Gallagher	Consultant in Child and Adolescent Psychiatry, Antrim
•	Mrs Bernadette Hamilton	Co-ordinator, Approved ASW Training Programme Northern Ireland
•	Dr Mary McClean	Carer Representative
•	Dr Artie O'Hara	Consultant Psychiatrist, Gransha Hospital
•	Mrs Maureen Piggot	Chief Executive, MENCAP
•	Dr Pauline Prior	Senior Lecturer, School of Sociology and Social Policy, QUB
•	Dr Oliver Shanks	Consultant Psychiatrist
•	Master Hilary Wells	Master, Office of Care and Protection

Co-opted to consider the Needs of People with Learning Disability

•	Dr Petra Corr	Consultant Clinical Psychologist, Muckamore Abbey Hospital
•	Dr Michael Curran	Consultant Psychiatrist, Foyle Trust
•	Dr Jennifer Galbraith	Consultant Psychologist, Foyle Trust
•	Mr Paddy McLoone	Assistant Principal Social Worker, Foyle Trust
•	Dr Caroline Marriott	Consultant Psychiatrist, Muckamore Abbey Hospital

Co-opted to consider the Needs of Adults with Mental Health Problems

•	Mr John James	User Representative
•	Dr Graeme McDonald	Consultant Psychiatrist, Mater Hospital

SUB-GROUP 2 - which considered Compulsory Assessment and Treatment, and Guardianship (under Part II), the role of the Mental Health Review Tribunal (under Part V) and the role of the Mental Health Commission (under Part VI)

Membership:

Convenor:	Professor David Bamford	Chair of the Review
•	Dr Paul Bell	Consultant Psychiatrist, South and East Belfast Trust
•	Dr Jim Campbell	Senior Lecturer in Social Work, QUB
•	Dr Michael Curran	Consultant Psychiatrist, Foyle Trust
•	Dr Noeleen Devaney	Medical Director, Down Lisburn Trust
•	Miss Brenda Donnelly	Official Solicitor to the Supreme Court
•	Mr Philip Gilpin	Solicitor
•	Dr Helen Harbinson	Consultant Psychiatrist, Ulster Community and Hospitals Trust
•	Mrs Phil Hughes	Principal Officer, Dementia Services, Homefirst Trust
•	Ms Michelle McMaster	Carer Representative
•	Mr Mervyn Morrow QC	Deputy Chair, Mental Health Review Tribunal
•	Mr Brendan Mullen	Director of Mental Health, Ulster Community and Hospitals Trust
•	Mrs Mary O'Boyle	Assistant Director, Mental Health, Holywell Hospital
•	Mrs Marion O'Neill	Chair, Mental Health Commission

The Sub-Group which considered Compulsory Assessment and Treatment, chaired by Dr Jim Campbell, also co-opted:

•	Mrs Christine Bateson	Crisis Response Team, Homefirst Trust
•	Mr Martin Daly	User Representative
•	Dr Mary McClean	Carer Representative

The Sub-Group which considered Guardianship, chaired by Mrs Phil Hughes, also co-opted:

•	Ms Marilyn Beare	Community Nursing Service Manager, Homefirst Trust
•	Mr Jack Chapman	Carer Representative
•	Dr Jennifer Creegan	Psychologist, Downshire Hospital
•	Ms Eileen Harvey	Clinical Services Manager, Down Lisburn Trust
•	Mrs Karen Howell	Assistant Principal Social Worker, Ulster Community and Hospitals Trust
•	Mr Jim McCluney	Senior Social Worker, South and East Belfast Trust
•	Dr Kerry Ng	Staff Grade Psychiatrist, Muckamore Abbey Hospital
•	Ms Claire Quigley	Mental Health Commission
•	Ms Angela Trainor	Carer Representative

- Other User Representatives in this Sub-Group did not wish to have their names disclosed.

The Sub-Group which considered the Mental Health Review Tribunal was chaired by Mr Mervyn Morrow QC

The Sub-Group which considered the Mental Health Commission, chaired by Dr Noeleen Devaney, also co-opted:

•	Dr Stephen Compton	Consultant Psychiatrist, Mater Hospital
•	Mr Patrick Convery	OT Services Manager, Foyle Trust
•	Miss Marie Crossin	Chief Executive, CAUSE
•	Mr Glenn Houston	Chief Executive, Craigavon and Banbridge Trust
•	Dr Mandy Irvine	Consultant Psychologist, Muckamore Abbey Hospital
•	Mrs Lucy McManus	Director of Nursing, Armagh and Dungannon Trust
•	Mrs Julie Thornton	Manager of the Registration and Inspection Unit, Northern Health and Social Services Board
•	Mr Jim Walsh	Mental Health Alliance Co-ordinator

SUB-GROUP 3 - which considered Consent to Treatment (under Part IV), the Management of Property and Affairs of Patients (under Part VIII) and Enduring Powers of Attorney

Membership:

Convenor:	Master Brian Hall	Master, Office of Care and Protection
•	Mrs Fiona Bagnall	Resident Magistrate
•	Mrs Maeve Bell	Carer Representative
•	Mrs Mairead Buckley	Office of Care and Protection
•	Mr Laurence Evans	Mental Health Services Manager, Daisy Hill Hospital
•	Miss Heather Gibson	Barrister at law
•	Mr John James	User Representative
•	Miss Linda Johnston	Solicitor
•	Mrs Rosalind Johnston	Deputy Official Solicitor
•	Dr Roger Manktelow	Lecturer, University of Ulster
•	Dr Caroline Marriott	Consultant Psychiatrist, Muckamore Abbey Hospital
•	Prof Roy McClelland	Chair of the Review
•	Dr Clare Monaghan	Consultant Psychiatrist, South Tyrone Hospital
•	Mr Tommy Monteith	Community Psychiatric Nurse, Foyle Trust
•	Mr Alastair Rankin	Solicitor
•	Mr Henry Toner QC	Bar Library

The Sub-Group which considered Consent to Treatment, chaired by Dr Clare Monaghan, also co-opted:

•	Dr Jim Anderson	Consultant Psychiatrist, Ulster Community and Hospital Trust
•	Ms Jacqueline Carey	User Representative
•	Mrs Martha McClelland	User Representative and Convenor, Experts by Experience Reference Group
•	Dr Michael Mannion	Consultant Psychiatrist, Holywell Hospital
•	Dr Sheelagh Mary Rea	Consultant Psychiatrist, Foyle Trust

SUB-GROUP 3 - which considered Offenders with Mental Health needs, including those with Personality Disorder

Membership:

Convenor:	Dr Fred Browne	Consultant Forensic Psychiatrist, Shannon Clinic
•	Mr Brian Archer	Solicitor
•	Mrs Angela Bell	Criminal Justice Division, NIO
•	Mrs Pat Best	Probation Board for Northern Ireland
•	Dr Ian Bownes	Forensic Psychiatrist, Tyrone and Fermanagh Hospital
•	Mrs Deborah Devaney	Carer Representative
•	Dr John Farnan	Forensic Medical Officer
•	Mr Brendan Fulton	Assistant Chief Probation Officer, Probation Board for Northern Ireland
•	Dr Geraldine Henry	Consultant Psychiatrist, Holywell Hospital
•	Mr George Keatley	Deputy Director, NI Court Service
•	Dr Harry Kennedy	Consultant Forensic Psychiatrist, Dublin
•	Mr Bill Lockhart	Chief Executive, Youth Justice Agency
•	Dr Philip McClements	Chief Medical Advisor (Prisons), NIO
•	Mr Noel McKenna	Carer Representative
•	Mrs Cathy McPhilips	Assistant Director of Mental Health
•	Dr Colin Milliken	Consultant Psychiatrist, Muckamore Abbey Hospital
•	DCI Gary Mullan	Police Service of Northern Ireland
•	Mrs Anne Rafferty	Criminal Justice Division, NIO
•	DSgt David Wallace	Police Service of Northern Ireland

Annex 3

THE BOURNEWOOD (HL) CASE

This case concerns Mr L who is incapable of giving consent or objecting to medical treatment. He had been cared for in Bournewood hospital for around 30 years until March 1994 when he was discharged to live with paid carers on a trial basis.

In July 1997 Mr L was removed from his existing carers in the community and re-admitted to Bournewood hospital as he had been agitated when making his weekly visit to a day care centre run by a local authority. In line with standard practice, Mr L was not compulsorily detained under the 1983 Act but admitted on an informal basis under the common law doctrine of necessity because he was compliant and did not resist admission. The consultant in charge of Mr L subsequently advised his carers on clinical grounds not to visit him due to concern that he would think he would be able to leave with them.

Mr L was not formally detained until December 1997 following a Court of Appeal ruling that the detention in July 1997 had been unlawful. Through his carers Mr L sought judicial review of the decision to admit him to hospital, a writ of habeas corpus to secure his release and damages for false imprisonment and assault. This was refused at first instance. Although Mr L successfully appealed to the Court of Appeal this decision was overturned in the House of Lords who held that he had not been detained.

The case was referred to the European Court of Human Rights (ECtHR). The Court considered that Article 5(1) of the ECHR requires the existence in domestic law of adequate legal protections and fair and proper procedures. Compulsory committals under the 1983 Act provide procedural rules on, amongst other things, who may propose admission, for what reasons and what kind of medical and other assessments are required. However, in contrast there are no fixed procedural rules relating to the admission or detention of compliant incapable patients.

Reliance on the doctrine of necessity for admission or treatment of such patients is arbitrary due to the lack of procedural safeguards and therefore, the ECtHR opined, unlawful. Such safeguards are required to protect individuals against any misjudgement or professional lapse of the relevant healthcare professional. The court held that Article 5(1) of ECHR was breached in Mr L's case and outlined the following types of procedural safeguards that they believed are required:

(1) procedures for fixing the purpose or basis of an admission (eg for assessment and for treatment) and who can propose admission;

(2) procedures for establishing time, treatment or care limits attached to an admission;

(3) procedures for continuing clinical assessment to ensure there is still a disorder warranting detention; and

(4) procedures for representatives being able to make objections or applications on behalf of the patient.

The ECtHR also found that it had not been demonstrated that Mr L had available to him a procedure to have the lawfulness of his detention reviewed by a court. Judicial review was the only method of challenge that was of any consequence and that was insufficient for the purpose of reviewing the lawfulness to detain at the time of Mr L's domestic proceedings.

At that time, before the Human Rights Act came into force, judicial review was not wide enough to adequately examine the merits of the clinical views as to the persistence of mental illness such as to justify detention. Therefore the court held that article 5(4) of the ECHR was also breached.

> (Extracted from The Adults with Incapacity (Scotland) Act 2000 Draft Guidance for Local Authorities on when to invoke the Act).

Annex 4

DEVELOPMENTS IN MENTAL HEALTH LAW – TREATMENT IN THE COMMUNITY IN SCOTLAND

COMPULSORY TREATMENT ORDERS UNDER THE MENTAL HEALTH (CARE AND TREATMENT) (SCOTLAND) ACT 2003

Compulsory Treatment may be given either in hospital or in a community setting (based on the least restrictive alternative) when the criteria for this are met (see paragraphs 4.43 and 4.44).

After the 28 day period of assessment allowed under a Short Term Detention Order, an application is made to a Tribunal for approval of a Compulsory Treatment Order. This must accord with the principles underlying the Act and take into account Advance Statements the person may have made with regard to treatment, the role of the named person and the provisions made for advocacy support.

The process of application is co-ordinated by and is the responsibility of a specially trained "Mental Health Officer" (MHO). The process is multi-disciplinary and requires in-depth consultation with all parties, including the patient at all stages. The application has two medical reports, the MHO's report and the Proposed Care Plan. The possible measures that may be authorised include the patient:

- to be detained in hospital;
- to receive medical treatment in or out of hospital;
- receive community care services or other services;
- to reside in a specified place;
- to afford access to MHO, RMO, and others; and
- to get permission from the MHO to change residence.

Some essential elements of the Care Plan may be identified as "recorded matters" and there is a responsibility on the RMO to report if these essential elements are not provided. There is a duty upon Health Authorities that these should be provided as required by the principle of reciprocity.

The definition of "Medical Treatment" is broad and includes nursing care, psychological intervention and rehabilitation (which includes education, training in work, habitation and social and independent living skills).

The contents of the Care Plan cover four key areas:

- the needs of the patient;
- the actions proposed to meet these;
- the objectives of these actions; and
- the parties who undertake responsibly to carry out all the actions.

Unmet need is also recorded. Emphasis is on the least restrictive alternative at all stages. The

Code of Practice emphasises the need for all involved in the delivery of care and treatment to work in close multi-disciplinary collaboration.

If a person does not comply with specific conditions – for example does not attend for medical treatment - then the Order allows the patient to be conveyed to an approved place for the purpose of receiving treatment. The person may be detained for up to six hours for treatment to be given,

If a person is not complying with measures in the community-based CTO, there are powers given to remove him to hospital for up to 72 hours in certain conditions and this period of detention may be extended if the Care Plan needs to be revised. The use of force in giving treatment under any circumstances is not permitted, other than for a patient in hospital.

The powers given are individual to the patient's needs and proportionate to the level of compulsion required (ie. least restrictive).

These measures were only put into operation in October 2005 and the Scottish Mental Welfare Commission, which monitors the operation and implementation of the Act, is visiting every person who is subject to a Community CTO to check whether elements of the Care Plan are indeed being provided. Meanwhile, the King's Fund has recently completed an independent survey of community-based Compulsory Treatment Orders (Lawton-Smith, 2006) (see paragraph 5.33).

Annex 5

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THE BAMFORD REVIEW OF MENTAL HEALTH AND LEARNING
DISABILITY (NORTHERN IRELAND)

PROMOTING THE SOCIAL INCLUSION OF PEOPLE WITH A MENTAL HEALTH PROBLEM OR A LEARNING DISABILITY

August 2007

FOREWORD

This further report from the Bamford Review covers the important area of promoting the social inclusion of people with a mental health problem or a learning disability. It complements, in particular, the Review's Human Rights and Equality of Opportunity report, which was published in October 2006. Together they set out the ethical values for the entire Review and its central vision of valuing people with a mental health problem or a learning disability and enabling them to enjoy their rights to full citizenship.

The report also fulfils the dual purpose of providing the Department of Health, Social Services and Public Safety's latest contribution to the Office of the First Minister and Deputy First Minister on the Promoting Social Inclusion initiative, which is part of the New Targeting Social Need strategy.

Preparation of the report has involved discussions with and contributions from several other Northern Ireland Departments, users of services, their carers and families. It makes a number of practical recommendations on how people with a mental health problem or a learning disability can lead more inclusive and meaningful lives.

We commend the report to you.

Roy J. McClelland (Professor)
Chairman,
Bamford Review

Leslie Frew
Director,
Mental Health and
Disability Services,
DHSSPS

CONTENTS

FOREWORD

ANNEXES

1. INTRODUCTION

Purpose

1.1 The purpose of this report is to identify the reasons why people with mental health problems or a learning disability are often excluded from the kind of everyday life that others take for granted and to make recommendations that will improve their inclusion in society.

Background

1.2 This review forms part of Northern Ireland's Promoting Social Inclusion policy, which encourages Government Departments to form inter-departmental groups to tackle key areas of social exclusion. As the Department of Health, Social Services and Public Safety (DHSSPS) had commissioned an independent Review of Mental Health and Learning Disability policy and legislation, it was agreed that this Review was the most appropriate vehicle to consider the social inclusion of people with a learning disability or mental health problems.

1.3 Promoting Social Inclusion involves the statutory, private and voluntary sectors. In particular, the contribution of the voluntary sector in terms the promotion of social inclusion of people with mental health needs and learning disability has been welcomed in terms of stigma, housing, employment and health.

Promoting Social Inclusion (PSI) Policy

1.4 The Northern Ireland Executive agreed that Promoting Social Inclusion involves Departments working together and with social partners:

- To identify and tackle factors which can contribute to social exclusion.
- To undertake positive initiatives to improve and enhance the life and circumstances of the most deprived and marginalised people in our community.

The Bamford Review of Mental Health and Learning Disability

1.5 The DHSSPS commissioned a Review of Mental Health and Learning Disability policy and legislation in October 2002. The main reasons for commencing the Review were:

- The focus of existing legislation was on treatment and care in hospitals rather than in the community.
- Increased expectations for amended legislation following reviews of mental health legislation in neighbouring jurisdictions.
- The requirement to ensure that legislation is updated to reflect human rights, equality and European legislation.
- Major changes in the modern methods of providing treatment and care.

1.6. A Steering Committee, initially chaired by the late Professor David Bamford, was established to oversee the Review. The Committee has representation from a wide range of professional interests, the voluntary sector, individuals, carers and includes members from neighbouring jurisdictions.

1.7. The vision of the Review is:

- Valuing those with learning disability and mental health problems, their rights to full citizenship, equality of opportunity and self-determination.
- Addressing the challenges facing people with mental health problems or a learning disability.
- A process of review, reform, renewal and modernisation of services that will make a real and meaningful difference to the lives of people with mental health problems or a learning disability and to their carers and families.

1.8. The key values of the Review are:

- Respect for people as individuals – through openness and honesty in the provision of information, respect and courtesy in individual interactions with individuals, partnership and empowerment in service planning and delivery – with Government, providers and the wider society each accepting their respective responsibilities.
- Demonstrating justice and fairness – resources for services should be allocated and managed according to criteria which are transparent, and which demonstrate equity.

1.9. The principles of the Review are:

- Partnership with users and carers in the development, evaluation and monitoring of services.
- Partnership with users in the individual assessment process, and in the development of their programme of treatment and care and support.
- Delivery of high quality, effective treatment, care and support.
- Equity of access and provision of services, including the needs of people from minority cultures, people with disabilities, people subject to the criminal justice system.
- Provision of services that are readily accessible.
- Delivery of continuity of care and support for as long as is needed.
- Provision of a comprehensive and co-ordinated range of services and accommodation based on individual needs.
- Taking account of the needs and views of carers, where appropriate, in relation to assessment, treatment, care and support.
- Provision of comprehensive and equitable advocacy support, where required or requested.
- Promotion of independence, self-esteem, social interaction and social inclusion through choice of services and opportunities for employment and social activities.
- Promotion of safety for individuals, carers, providers and members of the public.
- Provision to staff of the necessary education, training and support.
- Services subject to quality control, informed by the evidence.

1.10. During the PSI review it was noted that there is a lack of local research in Northern Ireland in promoting social inclusion for people with mental health problems or a learning disability.

2. VISION, PRINCIPLES, POLICIES AND LEGISLATION

2.1. The Promoting Social Inclusion Group (see Annex 1) decided that it was important to set a vision and principles for social inclusion that were easy for everyone to understand. The vision and principles would operate within the wider national and international legal and policy context.

Vision – 'Just Like You'

2.2. People with a learning disability or mental health problems can often be denied access to services that everyone takes for granted. The 'Just Like You' vision is that people with a learning disability or mental health problems are the same as you, with the same needs for everyday life including education, employment, housing, health, transport and a social life.

Principles – 'Just Like You'

2.3. The 'Just Like You' principles identify the key areas of life that people with a learning disability or mental health problems require the same access and opportunities as everyone else.

Employment

2.4. We need employment to meet our potential and provide economic opportunities in life – 'Just Like You'.

Education

2.5. We need education to motivate us to achieve our potential, build our confidence, enrich our lives, and provide the foundation for an inclusive society – 'Just Like You'.

Housing

2.6. We need the opportunity to access decent, affordable housing in safe and sustainable communities that contribute to our improved health and social well-being – 'Just Like You'.

Health

2.7. We need to be provided with opportunities to promote our health and mental well-being and have easy access to quality health and social services, when required – 'Just Like You'.

Transport

2.8. We need to have adequate transport to access employment, education, health and provide opportunities to meet families and friends – 'Just Like You'.

Social Life

2.9. We need to be able to fully participate in social activities with friends, family and the local community – 'Just Like You'.

Mental Health Declaration for Europe

2.10. The Ministers of Health of Member States in the European Region of the World Health Organisation agreed a Mental Health Declaration for Europe in January 2005. The statement acknowledged that mental health and mental well-being are fundamental to the quality of life and productivity of individuals, families, communities and nations.

2.11. A key priority in the Mental Health Declaration is to 'collectively tackle stigma, discrimination and inequality, and empower and support people with mental health problems and their families to be actively engaged in this process'.

The Madrid Declaration

2.12. In March 2002, a European Congress of People with Disabilities was held in Madrid under the Spanish Presidency. An outcome of the Congress was the so-called 'Madrid Declaration'.

2.13. The vision of the Madrid Declaration: "Our vision can best be described as a contrast between this new vision and the old vision it seeks to replace:

(a) Away from disabled people as objects of charity...and towards people with disabilities as right holders.

(b) Away from people with disabilities as patients... and towards people with disabilities as independent citizens.

(c) Away from professionals taking decisions on behalf of people with disabilities... and towards independent decision making and taking responsibilities by people with disabilities on issues which concern them.

(d) Away from a focus on individual impairments... and towards removing barriers, revising social norms, policies and promoting a supportive and accessible environment.

(e) Away from labelling people as dependents or unemployable... and towards an emphasis on ability and the provision of active support measures.

(f) Away from designing economic and social processes for the few... and towards designing a flexible world for the many.

(g) Away from unnecessary segregation in education, employment and other spheres of life... and towards integration of people with disabilities into the mainstream.

(h) Away from disability policy as an issue that affects specialised ministries...and towards inclusion of disability policy as an overall Government responsibility".

Improving the Life Chances of Disabled People

2.14. The Department of Work and Pensions Strategy Unit's report, 'Improving the Life Chances of Disabled People', was published in January 2005 as agreed Government policy. The report set out an ambitious vision for improving the life chances of disabled people over the next twenty years.

2.15. The report focuses on four key aspects of disabled people's life chances: independent living; early years and family support; transition to adulthood; and employment. The practical measures are designed to:

- Increase disabled people's ability to live independently - to enjoy increased choice and control over how their needs are met through individualised budgets - and to have the opportunity of a full home, work and community life.
- Enable young disabled children and their families to enjoy 'ordinary' lives, through access to childcare, early education and early family support, to enable them to care for their child effectively and remain socially and economically included.
- Support disabled young people and their families through the transition to adulthood. Transition will be better planned around the needs of the individuals and service delivery will be smoother across the transition.
- Increase the number of disabled people in employment while providing support and security for those unable to work. Employers will be able to access the right advice and information.

The UN Convention on the Rights of Persons with Disabilities

2.16. The UN adopted a new draft treaty in August 2006 giving greater rights to disabled people around the world. The United Nations Convention on the Rights of Persons with Disabilities requires:

- Participating countries to change laws and ban discriminatory customs and practices.
- Disabled people to have an equal right to life.
- Equal rights for disabled women and girls.
- Protection for children with disabilities.
- A right to own and inherit property, to control financial affairs and have equal access to financial services.
- Disabled people not to be deprived of their liberty 'unlawfully or arbitrarily'.
- Medical or scientific experiments without consent to be banned.
- An end to enforced institutionalisation.
- Freedom from exploitation, violence and abuse.
- A right to privacy and access to medical records.
- Countries to remove barriers to accessing the environment, transport, public facilities and communication.
- A right to independent living.
- Essential equipment to be made affordable.
- A right to an adequate standard of living and social protection.

- An end to discrimination relating to marriage, family and personal relationships.
- Equal access to education.
- An end to discrimination in the job market.
- A right to equal participation in public life.
- A right to participate in cultural life.
- Developing countries to be assisted to put the convention into practice.

UN Convention on the Rights of the Child

2.17. The human rights of children and the standards, to which all governments must aspire in realizing these rights for all children, are detailed in one international human rights treaty: the UN Convention on the Rights of the Child.

2.18. The Convention has been ratified by almost every country in the world and by ratifying the Convention governments have committed themselves to protecting and ensuring children's rights.

2.19. The Convention on the Rights of the Child is a universally agreed set of non-negotiable standards and obligations. It spells out the basic human rights that children everywhere – without discrimination – have: the right to survival; to develop to the fullest; to protection from harmful influences, abuse and exploitation; and to participate fully in family, cultural and social life. Every right spelled out in the Convention is inherent to the human dignity and harmonious development of every child. The Convention protects children's rights by setting standards in health care, education and legal, civil and social services. These standards are benchmarks against which progress can be assessed. States that are party to the Convention are obliged to develop and undertake all actions and policies in the light of the best interests of the child.

2.20. The Convention on the Rights of the Child is the first legally binding international instrument to incorporate the full range of human rights – civil and political rights as well as economic, social and cultural rights. On 20 November 1989, the governments represented at the General Assembly agreed to adopt the Convention into international law.

The Disability Discrimination (Northern Ireland) Order 2006

2.21. The Disability Discrimination (NI) Order 2006 strengthens and extends the coverage of the Disability Discrimination Act 1995, increasing the scope of legislation to include more people with disabilities. For example, people with mental health problems will no longer have to prove their condition is "clinically well-recognised". The new laws will also provide extra protection for disabled people in other areas such as private clubs and in discriminatory job advertisements. Under the new laws disabled people living in rented premises will now find it easier to have their homes adapted to meet their needs. Transport will become more accessible to disabled people as the legislation will require all trains to be fully accessible by 2020. The legislation also introduces an important provision that will enable lifting of the transport exemption from Part III of the Disability Discrimination Act 1995 for land-based public transport, vehicle hire, breakdown services and leisure and tourism transport vehicles.

The Order also extends current legislation to bring the functions of public authorities within the scope of disability legislation for the first time and imposes a new duty on them to promote positive attitudes towards disabled people and encourage their participation in public life. The extension of the Act in this way will impose further duties on the public sector not to discriminate against disabled people across the whole range of its public activities.

Northern Ireland Act 1998 – Section 75

2.22. The Northern Ireland Act 1998 places on public bodies a duty to promote equality of opportunity and this includes people with mental health problems and learning disabilities. The relevant text is:

"75. - (1) A public authority shall in carrying out its functions relating to Northern Ireland have due regard to the need to promote equality of opportunity-

(a) Between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation.

(b) Between men and women generally.

(c) Between persons with a disability and persons without.

(d) Between persons with dependants and persons without.

(2) Without prejudice to its obligations under subsection (1), a public authority shall in carrying out its functions relating to Northern Ireland have regard to the desirability of promoting good relations between persons of different religious belief, political opinion or racial group."

3. STIGMA

Background

3.1. Mental health problems affect people of all ages, in all kinds of jobs and at all educational levels. Often, the only way to know whether someone has mental health problems is if they tell you. The majority of people are unaware of how many people with mental health problems they know and encounter every day (it is estimated in Great Britain that 1 in 6 people have a mental health problem at any one time).

3.2. Stigma is a reality for people with a mental illness or a learning disability and it is reported that how others judge them is one of their greatest barriers to a complete and satisfying life. Society feels uncomfortable about mental health problems and it is not seen like other health problems such as heart disease and cancer. Due to inaccuracies and misunderstandings, sometimes people have been led to believe that an individual with a mental illness has a weak character or is inevitably dangerous.

3.3. We all have an idea of what someone with a mental health problem or a learning disability is like, but society and the media have distorted most of our views and interpretations. Newspapers often portray people with mental health problems as "psychos", "nutters" or loony and news coverage focuses on the violence and mental illness. This type of language distorts people's views and reinforces stigma.

3.4. A Survey of the Stigma, Taboos and Discrimination Experienced by People with Mental Health Problems, 'Not Just Sticks & Stones'(Jim Read and Sue Baker November 1996) found that:

- A large majority (69%) of people had been put off applying for jobs for fear of unfair treatment.
- Half (50%) of people felt unfairly treated by general health care services.
- Almost half (47%) of the people had been abused or harassed in public, and some (14%) had been physically attacked.
- Almost half (45%) of people thought that discrimination had increased in the last 5 years compared with 18% who thought it had decreased.
- A third of people (34%) said they had been dismissed or forced to resign from jobs.
- A third (33%) complained that their GP had treated them unfairly.
- A quarter (25%) of people felt at risk of attack inside their own homes and a quarter (26%) of people were forced to move home because of harassment.
- A quarter (25%) of people had been turned down by insurance or finance companies.
- Almost a quarter (24%) of parents said their children had been teased or bullied, or that they were afraid it would happen.

3.5. The Mental Health Foundation's survey of people's experiences of stigma and discrimination as a result of mental distress, 'Pull Yourself Together!' (2000) found that:

- 70% had experienced discrimination in response to their own mental distress or in response to that of a relative or friend.

- The fear of stigma and discrimination had prevented individuals from telling others about their own mental distress - 66% said that they could not tell some people.
- The main sources of discrimination in response to people's own mental distress were from within the family (56%), and from friends (52%). Many people referred to name calling, labelling and unhelpful instructions such as 'Pull Yourself Together'.
- Some people reported that they had not told their family (42%) or friends (42%) about their experience of mental distress. People were afraid that family members would not understand or would be judgmental towards them.
- The workplace appeared to be the second most likely place to receive discrimination (30%). A lack of understanding was most frequently cited as a reason for this. Some respondents gave very serious examples of discrimination, including a number of people who said that they had been dismissed or forced into redundancy, due to their experience of mental distress. Fear of discrimination also prevented people from disclosing details of their mental health history on application forms (e.g. for employment and insurance).
- A significant number of respondents reported discrimination from their GPs (44%) and other healthcare professionals (32%) in response to their own mental distress.
- A number of people (19%) reported that they were unable to talk to their GP about their own mental distress.

3.6. Repeated surveys of learning disability in Ireland and Britain have highlighted how little contact neighbours have with community residences or day centres (McConkey, 1986). People with learning disability are still perceived as belonging to the learning disability services and not as belonging to the community. Many community facilities for people with learning disability are separate from the community in which they are sited.

3.7. The 'ordinary life' philosophy for people with a learning disability means people living in ordinary houses, with support from paid staff, joining in neighbourhood leisure pursuits and finding employment in local businesses (Sutcliffe, 1990). Antagonistic reactions from an poorly informed public threaten the successful social inclusion of people with a learning disability in the community. An informed community is an important outcome in its own right, but more significantly it is a step towards an involved community.

Qualitative Survey of Users and Carers

3.8. In a Qualitative Survey of users and carers in Northern Ireland it was discovered that it was routine to not disclose mental health problems, for example for jobs applications and driver licences etc.

Where are we now?

3.9. The Scottish Executive's National Programme for Improving Mental Health and Well-Being has been working nationally and locally, since its launch in October 2001, to raise the profile of, and to support further action in, mental health improvement (promotion and prevention), to address the stigma of mental ill-health and to prevent suicide in Scotland. A National Advisory Group, chaired by the Minister for Health and Community Care, was established in January 2002 to advise and steer the work of the Programme.

3.10. In England, the National Institute for Mental Health in England (NIMHE) published a review in May 2004, of what works to address stigma and discrimination on mental health grounds. The key principles in tackling stigma were:

- Involving people with first-hand experience of discrimination and carers throughout.
- National programmes that support local activity.
- Targeting specific audiences.
- Long-term planning and funding.
- Monitoring and evaluation.

3.11. In June 2004, NIMHE launched 'From Here to Equality', a five-year plan to tackle stigma and discrimination. It is based on international evidence of what works and brings together agencies from the voluntary sector and Government. This programme will be nationally co-ordinated, but will be implemented at regional and local level. Initial target audiences will be young people, the media, health and social care, public sector organisations, and private and voluntary sector organisations (see www.nimhe.org.uk).

Recommendations

1. There is an ongoing need to monitor negative stereotypes within the community and to change the attitudes that reinforce these negative stereotypes. Communities need to be educated to ensure the successful social inclusion of people with a mental health problem or a learning disability in their community

2. There is a fundamental need for a campaign to challenge the images that communicate negative stereotypes. The campaign needs to directly involve people with first-hand experience of discrimination, target specific audiences and monitor and evaluate its effectiveness.

3. All service providers must be encouraged to provide information in a form that is understood by people with mental health problems or a learning disability.

4. There is a need to establish a group to address the stigma associated with mental health problems and learning disabilities.

4. EMPLOYMENT

Background

4.1. Long-term unemployment is both a key characteristic and a primary economic cause of social exclusion and, in consequence policies to reduce work exclusion are crucial to creating a more inclusive society.

4.2. Only 36% of disabled people are in employment within Northern Ireland compared to 77% of non-disabled (Northern Ireland Labour Force Survey: Autumn (Sep-Nov) 2004).

4.3. People with a learning disability or mental health problems are more likely to be unemployed than other people. The Northern Ireland Health and Social Well-being Survey 2001 indicates that the unemployed were almost twice as likely to show signs of a possible mental health problem (30%) as those in employment (16%).

4.4. Data about disabled people from the Labour Force Survey show that 628,000 adults of working age in Great Britain regard mental disorder as their main disability. Only 21 per cent of these adults are in employment – the lowest rate for any group with disabilities (Office for National Statistics, Labour Force Survey, 2002).

4.5. Mental and Behavioural Disorders are the largest diagnosis group (36.5%) for claimants to incapacity benefits in Northern Ireland (Northern Ireland Summary of Social Security Statistics 2004). Statistics are collected for both mental health and learning disability combined and it is not possible to breakdown these figures.

4.6. The Report-Safety First: National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (2001) stated that in relation to suicide of people with mental illness in Northern Ireland 60% were either unemployed or long term sick.

4.7. In England and Wales, the Social Exclusion Unit's report 'Mental Health and Social Exclusion', June 2004, highlighted particular issues concerning employment:

- Due to stigma and discrimination fewer than four in ten employers would consider employing someone with a history of mental health problems, compared to more than six in ten for candidates with physical disability.
- Three-quarters of employers would not consider employing someone with schizophrenia, even though schizophrenia can be controlled with medication and would not require physical adaptations to the work environment.
- One-third of people with mental health problems report having been dismissed or forced to resign from their job, because of their previous psychiatric history and more than two-thirds had been put off applying for jobs for fear of unfair treatment.
- There is anecdotal evidence of some employment contracts including, within their definition of gross misconduct, clauses such as "if you become of unsound mind or a patient under the Mental Health Act 1983" which would trigger instant dismissal.

4.8. People with long-term mental health problems have the lowest employment rate of any of the main groups of disabled people – according to the Labour Force Survey definition only 24 % are currently in work in England. By comparison, research from the US found that with effective rehabilitation support, up to 58 % of adults with severe and enduring mental health problems are able to work using the Individual Placement and Support approach.

4.9. Many people with a learning disability aspire to having a job and increasing numbers of parents share this aspiration for their teenage sons and daughters. Traditionally, the majority of school leavers from Severe Learning Disability schools have been placed in day centres commissioned by health and social services agencies.

Good Practice Examples

Southwest London and St. George's Mental Health NHS Trust: *In this service Occupational Therapists act as clinical vocational leads, working with specialist services to increase access to employment and education for clients. There is a vocational support worker on each team. Prior to intervention > 60% clients Seriously Mentally Ill group were not engaging in any work, education or structured activity. This reduced to 20% after 1 year's experience on the programme. 888 people have specific vocational input in the period from Nov. 01 – Nov. 02. After 1 year 469 were involved in open employment.*

Action Mental Health's New Horizons and Accept: *These services provide vocational training, personal development and employment programmes to people with mental ill health. AMH's clients have a wide choice of programmes aimed at helping them lead inclusive lives in their communities and wherever possible to find jobs. The training they receive is accredited and enables them to acquire vocational skills as well as regaining self-confidence and self-esteem. Employment preparation programmes include advice on job search, completion of employment application forms, interview skills and work experience placements. More than 1000 people are assisted each year.*

Action Mental Health's Careers programme: *The programme is funded by Peace 2 monies, provides help for people with a history of mental illness who are in low paid jobs. It is essentially a career advancement programme aimed originally at the Greater Belfast area and more recently in North Antrim. The programme enables participants to acquire new skills and compete successfully for better paid jobs. More than 40 people are assisted each year.*

The programme operates in partnership with employers who have given their full support. Employers are given advice on how to make adjustments for people with mental ill health and how their potential might be developed. Employers are also advised on how to raise awareness of mental health issues amongst their workforce. In this way mindsets are changed and the stigma attached to mental illness is reduced.

User perspective

Catherine works part-time for Dunnes Stores in Newry. She has worked for Dunnes since 1998.

As a member of Mencap's Northern Ireland Board Committee, Catherine guides and supports the work of Mencap in Northern Ireland - a voluntary organisation that provides a range of services, supports a membership network of over 60 local groups and campaigns for equal chances for people with a learning disability. Catherine is Vice Chairperson of the Committee and of Mencap in Northern Ireland. Catherine also chaired the 2005 Mencap in Northern Ireland conference, which was attended by over 130 people.

Catherine is Chairperson of Mencap's Southern District Committee. The District Committee brings together everyone with an interest in learning disability to find out about local needs and to campaign on issues in the area.

Catherine plays an active role in the current Review of Mental Health and Learning Disability - as a member of the Learning Disability Working Committee and as a member of Equal Lives, a group of people with a learning disability, established to advise and inform the Review.

Talking about the Review of Mental Health and Learning Disability, Catherine has said "It is important for me to speak up and be a voice for all people with a learning disability. I hope that, together, we can change other people's ideas on what people with a learning disability can do".

Qualitative Survey of Users and Carers

4.10. A Qualitative Survey of users and carers in a number of voluntary organisations in Northern Ireland (Annex 2) identified a number of employment issues for mental health users.

4.11. The Survey identified that there is little support for employees with mental health problems and that employers are not equipped to identify or deal with people with mental health problems.

4.12. There are few employers that have policies on promoting good mental health in workplace.

4.13. There is a fear of discrimination by employers, which leads to people not informing their employers of mental health problems.

4.14. The survey identified that the benefits system is a major risk in moving to employment. It is difficult to get benefits in the first place. If a person in receipt of benefits gains employment and gives up their benefits, but then becomes unwell again, their benefits may not be renewed or they may receive a lower level of benefit than before. These risks can inhibit people from seeking employment. There have been recent improvements in social security rules, but the rules remain complex and a barrier to people moving from incapacity benefit into work.

4.15. Employment opportunities are normally limited to low skill work. While people from all walks in life, representing the full spectrum of abilities and skills, can suffer from mental health problems, it can be extremely difficult to return to their previous jobs.

Where are we now?

4.16. One of 4 key strategic areas for the Department for Employment and Learning (DEL) is 'Helping People into Work'. DEL has a particular focus on assisting people with disabilities to prepare for work, to obtain and retain employment. DEL has a dedicated Disablement Advisory Service (DAS) to provide an employment service specifically for people with disabilities. The service is provided through Jobs and Benefits Offices and JobCentres, and is supported by an Occupational Psychology Service. The service is pan-disability, and includes a good deal of activity as support for clients with a learning disability and mental health problems. It is the role of DAS to:

- Provide an employment service for adults with disabilities who need special help.
- Help disabled people find and retain employment and to support them with a range of programmes, tailored to meet their needs.
- Help employers retain disabled people in work and develop employment policies in line with the Employment Right of the Disability Discrimination Act 1995 (DDA).

4.17. The main activities include:

Working with Employers

- Visiting employers to promote the abilities of disabled people and to secure employment opportunities.
- Promoting the range of DAS help available, including New Deal for Disabled People (NDDP), Access to Work (NI) and the Job Introduction Scheme.
- Advising on the retention of disabled employees in the workplace.

Working with Disabled Adults

- Maintaining an active caseload of jobseekers and, through an action planning process, providing help to enable the client find suitable employment or training placements.
- Establishing rapport with disabled jobseekers in order to help them reach their full potential in the workplace.
- Acting as New Deal Personal Adviser to disabled clients in the 18-24 year old, 25+ and 50+ programmes.
- Working as New Deal Personal Adviser for severely disabled clients, who are part of the NDDP target group and give them benefits information using the Integrated Benefit Information System (IBIS).
- Providing appropriate help under the Access to Work (NI) scheme.
- Providing support under the full range of DAS programmes i.e. Employment Support, Job Introduction Scheme, NDDP, Access to Work (NI) specialist training, employment assessment.

Working with Voluntary sector/Disability Sector/Health Professionals etc.

- DAS works very closely with this network, through a programme of visits, presentations etc Disablement Employment Advisors (DEAs) establish contact with the above sectors in their local areas to encourage referral of people with disabilities who want and need the help of DAS to find, keep or prepare for work.

Job Clinics

- Job Clinics are a partnership between DAS, Action Mental Health and Occupational Therapists (OT) in various HSS Trusts. They exist to help people with mental health disability progress through training and where appropriate into employment. JobClinics aim to pool the expertise in the three partners involved to best meet the needs of the client. Professional medical advice and employment assessment are accessed quickly through this system. The main referral agent is the OT although any of the partners can raise referrals. The partners have agreed defined roles within JobClinics and work through a Steering Group made up of key representatives from each of the member organisations.

Vocational Training

- DAS provides funding for a range of vocational training which is delivered by a number of disability organisations. DEL also offers the Jobskills programme which, through Jobskills Access, has particular support for young people facing particular difficulties, including disability.

Strategic Dialogue with Disability Sector

- DEL has initiated a strategic dialogue with the disability sector about the programmes and services offered by DAS. The Dialogue is being led by a Steering Group, which includes organisations representing people with learning disability and mental health problems, providing excellent opportunities for relevant organisations to help to shape provision.

4.18. The development of vocational training and the introduction of Supported Employment to Northern Ireland have opened up new possibilities for improving the employment prospects of people with a mental health problem or a learning disability:

- The Department for Employment and Learning's DAS provides assistance to people with a disability to access employment. Programmes on offer include Access to Work, Employment Support, Job Introduction Scheme and NDDP. Mainstream programmes like Jobskills and Worktrack are also available. Significant numbers of young people with a learning disability enter the Jobskills Programme.
- Access to these programmes can be limited by factors such as admission criteria, outcomes required, duration of the programme and the pattern of provision.
- There has been considerable growth in Supported Employment in Northern Ireland over the last decade. The Northern Ireland Union of Supported Employment has over 15 non-statutory agencies in its membership and many other day centres are involved in this work. A number of other approaches to securing paid work have also

developed including vocational training and social enterprises. Evaluations of such schemes have evidenced the benefits to individual participants, although few of the trainees had made the transition to paid work. European monies from either the Building Sustainable Prosperity or Peace Programmes have funded most of this provision. Urgent consideration needs to be given to mainstreaming the funding and the learning.

4.19. A range of external factors impinge on the potential for men and women with a learning disability gaining employment including; inflexible rules in relation to benefits, absence of clear intra-agency partnership and low expectations.

4.20. Department of Employment and Learning and the Social Security Agency are currently piloting 'Pathways to Work'. This work aims to encourage and support those people with long term ill-health back to work. Major reform to Incapacity Benefit is due to come on stream during 2008. The recent Department of Work and Pensions green paper 'A new deal for welfare: empowering people to work' recognised the particular difficulties faced by people with mental health problems or a learning disability. There is, however, little detail as to how the new arrangements will specifically work for people with mental health problems or learning disabilities.

Recommendations

5. The Labour Force Survey (2002) indicated that only 21% of people with a mental health problem or a learning disability are in employment yet research from the US found that with effective rehabilitation support, up to 58 % of adults with severe and enduring mental health problems are able to work using the Individual Placement and Support approach. Therefore the Northern Ireland target should be at least 50% of people with mental health problems or a learning disability should be in full time employment.

6. Employment Advisors should work with community mental health teams and community learning disability teams to provide pathways to employment.

7. European monies have funded a number of supported employment positions and Departments should mainstream this funding, where it has been shown to achieve positive outcomes.

8. Permitted work rules for Incapacity Benefit and Severe Disablement Allowance should be further improved, simplified and promoted effectively to reduce the barrier from moving from benefit to work. Returning to work should be on a voluntary basis and people should not be disadvantaged if their condition changes and prevents them from continued working.

5. HOUSING

Background

5.1. The Office for National Statistics report, "Better or worse: a longitudinal study of the mental health of adults living in private households in Great Britain", 2003, has provided estimates for the prevalence of mental disorders among people aged 16 to 74 years living in private households. The survey included evidence of neurotic disorders, psychotic disorders, alcohol problems and drug dependence. In this study, the proportion of adults found to have at least one neurotic disorder was 17% and the figure for assessed psychotic disorder was 0.4%. People who were of lower socio-economic status were less likely to recover from common mental disorder, as were the long term sick and disabled and the unemployed. The study found an annual incidence of suicidal thoughts of four per cent overall (three per cent among men and five percent among women). Incidence was highest among 16-24 year olds, 10 per cent of them reported onset of suicidal thoughts compared with 4-6 per cent of those in other age groups.

5.2. The ONS Survey collected data on the housing and household characteristics of people with mental health problems. The findings give an overall picture of housing status and reveal some key differences between people with mental disorders or substance dependency and those recorded as having no such disorder or dependency. The findings are contained in a separate report, 'The Social and Economic Circumstances of Adults with Mental Disorders' (Meltzer, H. 2002), the main findings being:

- People with a mental disorder or dependency were much more likely to be living in rented accommodation (38% compared to 24% in the no disorder group). Among those with a psychotic disorder, almost two-thirds (62%) were in rented accommodation and just under half (49%) were living in accommodation rented from a housing association or local authority.
- People with a mental disorder or dependency were more likely to be single, divorced or separated and less likely to be married. The group with a probable psychotic disorder had the highest percentages of divorced and separated people: 26% and 7% respectively, compared with the sample average of 8% and 3%.
- Lone parents made up 9% of the group with a neurotic disorder, compared to 4% of the no disorder group. Among those with a psychotic disorder, 43% were living in a one-person family unit (which includes certain types of shared household), almost three times the rate for those with no disorder (15%). While 38% of people with a psychotic disorder actually lived alone, the figure for the sample as a whole was only 12%.
- People with a disorder were more negative than the no disorder group about the standard of their accommodation: 11% and 5% respectively said they were very dissatisfied. Those with a disorder were also more likely to describe the state of repair of their home as poor: 9% compared with 4%. The most frequent complaint about housing was lack of space; this was reported by 20% of all respondents and about 30% of those with a neurotic disorder.
- 8% of people assessed as having a mental disorder felt that their health was made

worse by their accommodation, compared with 2% of the no disorder group. This figure increased to 14% for those with a probable psychotic disorder.

- Around 12% of people with a mental disorder had doubts about the security of their accommodation (i.e. whether they could stay there indefinitely), compared to 6% of the overall sample. The main reasons given for feeling insecure were: financial problems (20%); lease running out (18%); illness (14%); domestic problems (8%); and problems with the landlord or agent (7%).

5.3. Poor housing, housing insecurity and homelessness have also been shown to have a profound impact on mental illness and mental health service use. Research evidence suggests that poorly housed and homeless people have more serious mental health problems and require more intensive service support, including more frequent hospital admissions.

5.4. Having a home is a basic human need. The Audit Commission (1994) found that:

- Poor housing is particularly common among people with mental health problems.
- Mental illness is a frequent cause of tenancy problems and tenancy breakdowns.
- Poor housing and inappropriate accommodation can lead to the development or exacerbation of mental health problems.

5.5. Suitable accommodation is a fundamental element of effective services to support people with mental health problems or learning disability. A number of principles need to be considered in order to ensure an appropriate range of accommodation and support:

- People with mental health problems or a learning disability should have a choice of the type of accommodation they wish to live in. This has to be balanced in relation to the degree of risk posed to themselves or others.
- Assessment of accommodation needs should be a component of an overall assessment.
- Support for people receiving mental health services should be available to people with mental health problems or a learning disability regardless of where they are accommodated.
- Providers of accommodation should receive training and should be supported regardless of whether the accommodation is statutory, voluntary or private.

5.6. People with mental health problems or a learning disability generally want the same kinds of housing that everyone wants and not housing that is identified as mental health or learning disability housing, however, the evidence indicates that this is not happening.

5.7. The provision of group housing for people with mental health problems or a learning disability needs to be re-considered because of the danger of becoming institutionalised, like the long-stay hospitals of previous generations. Specialised housing can stigmatise people with a learning disability or mental health problems preventing successful integration into the community.

5.8. Supporting individuals in suitable housing in ordinary settings will help them gain access to a wide range of mainstream services and resources.

5.9. People who require support to stay in their own or rented accommodation may require essential support at a practical level to ensure the maintenance of the tenancy, e.g. home help, mental health support workers, learning disability support workers. Those who need respite on a short-stay basis to prevent acute admission may require emergency or non-emergency respite. Non-emergency respite may be required to accommodate people whose mental health is deteriorating and who require input from experienced staff over a period.

5.10. Crisis diversion/non-hospital accommodation may be provided as part of Crisis Response to prevent inappropriate admission to hospital.

5.11. People with challenging behaviour require specialist facilities with high staffing levels. It is important that the layout of the accommodation provides adequate personal space and there is access to daytime occupations and intensive staff support. Staff require specialist training in relation to dealing with challenging behaviour and potential violence.

5.12. Homeless people and rough sleepers present particular challenges. A recent study in Belfast identified some kind of mental health problems among 86% of single homeless people. (McGilloway S, Donnelly M (1996). 'Don't Look Away'. Homelessness and Mental Health in Belfast. The Health and Health Care Research Unit, Queen's University, Belfast).

5.13. Homelessness may have been caused or exacerbated by their mental health problems. Some may have been rejected from accommodation as a result of their mental illness or degree of challenge posed to staff. Some may have become displaced because of their mental health problems. Many have dual diagnosis. It is essential that homeless mentally ill people have access to mainstream services at primary and secondary care level. Accident and Emergency Services provide an important access point to care for homeless mentally ill people. Good communication between generic and mental health services is essential if effective interventions are to be made.

5.14. Discharge protocols in mental health services in Northern Ireland require further refinement to ensure that people leaving mental health facilities have appropriate accommodation on discharge. Close co-operation is required between Housing and Mental Health Services.

Learning Disability

5.15. Nearly all children with a learning disability (up to 19 years of age) live in family homes either with natural, adoptive or foster parents (McConkey, Spollen and Jamison, 2003).

5.16. Adults with a learning disability in Northern Ireland live in the family/own home (79%), residential home (17%) or hospital (4%).

5.17. The bulk of people live with family carers (66%), although a small proportion have their own accommodation (10%) or live with a spouse/partner (3%). Around 450 are resident in hospitals (mostly learning disability hospitals) and on average will have lived there for 20 years.

5.18. Nearly 1900 people are in some form of residential provision and have lived there for around 8 years on average. Comparable figures across these 3 forms of provision for the Republic of Ireland (Health Research Board, 2003) are: hospitals (4%); residential services (5 day and 7 day) (39%); community (57%).

5.19. In Great Britain, an estimated 63% of adults live in private households and 37% in some form of residential accommodation. The numbers living in long-stay hospitals are now less than 1% (Kavanagh and Opit, 1999). This data suggests that over twice as many adult people are in residential provision in Great Britain and in the Republic of Ireland than in Northern Ireland.

Qualitative Survey of Users and Carers

5.20. The Qualitative Survey of users and carers in a number of voluntary organisations in Northern Ireland identified a lack of knowledge about housing services for people with a learning disability or mental health problems.

5.21. It also identified a lack of local choice in the type of supported housing available and the absence of a seamless service between Housing and Social Services.

Good Practice Example

Following a successful pilot scheme, the Multidisciplinary Homeless Support Team (MDHST) was set up in Belfast (2005) and managed by Extern, a voluntary organisation. It is funded by the Northern Ireland Housing Executive, Health and Social Services Trusts, the Eastern Health and Social Services Board and the Probation Board for Northern Ireland. This team covers multiple disciplines including learning disability, addiction, family and childcare, young people, older people and has incorporated a floating support element, to sustain those who secured tenancies.

The focus of much of the work is with people with mental health problems. The 2005/06 statistics highlight this, with 330 of the total 1070 referrals having mental health problems as a primary issue and an additional 375 having mental health problems as a secondary issue. The MDHST has also received 33 referrals for clients with a learning disability as a primary issue. In many cases, the issues are very complex and the clients have been excluded from traditional service provision, advocacy and negotiation along with a commitment to support the client continues to be a major part of the Team's success.

Having a closer relationship with the Housing Executive has made a significant impact for the service users with assessment, planning and support being co-ordinated earlier and more effectively, resulting in more suitable and sustainable accommodation being located. The team is more than a housing assessment team; the focus is on the individual client need.

Where are we now?

5.22. The Department for Social Development (DSD) is committed to providing more information in a form that is understood by the recipient.

- To foster better communication between all those involved in providing services.
- To attempt to get supported housing provided as an integral part of general housing provision.

5.23. To continue to involve the complex needs tenants in all areas of the service, the Northern Ireland Housing Executive (NIHE) is responsible for establishing the needs of tenants, including maintaining a waiting list for complex needs tenants, having assessed those requirements. Supported Housing schemes for people with an array of special needs, but including those with mental health or learning disabilities, form an integral part of the Social Housing Development Programme (SHDP). Certain Housing Associations actively try to develop schemes which mix general needs (e.g., families) with dwellings for people with special needs, e.g., mental health or a learning disability.

5.24. To continue to break down barriers in the community, in terms of housing, forms part of the consultation process carried out by Housing Associations in helping the community to understand the need for schemes for people with mental illness or a learning disability (and indeed other special needs).

5.25. To foster better communication between all those involved in providing services, regular meetings take place between all parties involved in the delivery of the SHDP (NIHE, DSD, Housing Associations and DHSSPS) in order to secure funding for Supporting People, which is key in the provision of support for people with these special needs.

5.26. The Department for Social Development has been leading on a cross-departmental cross-sectoral working group, set up to consider homelessness in the context of Promoting Social Inclusion. This report details a number of recommendations which address the needs of people who are homeless, including those with mental health problems and learning disabilities.

Recommendations

9. DSD and housing providers should develop a housing strategy to ensure people with mental health problems and learning disabilities can, where possible, live in the accommodation of their choice, subject to normal financial constraints.

10. People with mental health problems or learning disabilities should have the choice to live independently but the use of specialised group housing has a role to play, for example as step-down accommodation after leaving hospital.

11. DSD should ensure participation of people with mental health problems or a learning disability in the planning of housing services

6. PERSONAL FINANCE

Background

6.1. People with mental health problems consistently identify personal finances as a major source of difficulty and distress (Davis: 1996; Dick: 1994; Dunn: 1999; Matthew Trust: 1997; Morgan et al: 2001; Rose: 1996; Sayce: 2000). Key factors contributing to this situation are:

- The impact of poverty and social exclusion on mental health and well-being.
- The high levels of benefit claiming amongst mental health individuals.
- The stigma of mental illness with institutions concerned with personal finances.
- The ways in which the stigma, discrimination and the impairments experienced by people with mental health problems impact on access to and management of personal finances.

6.2. The association between mental ill-health, poverty and deprivation is well established. People living on incomes below the average wage are twice as likely to develop mental illness as people on average and higher incomes. High socio-economic status has been found to decrease the likelihood of experiencing serious depressive episodes. Adults in the lowest social class are four times as likely to experience this form of mental distress compared with adults in the highest social class (Howarth et al: 1999; Gordon et al: 2000; ONS: 2000; Palmer et al: 2002; Payne: 2000). Surveys of people with mental health problems have confirmed that the majority of individuals live on low incomes and consider that their mental health problem has contributed to their income level (Dunn: 1999; Hogman & Chapman: 1998; MIND: 1998; Morgan et al: 2001).

6.3. People living in economic hardship on a long term basis are more likely to be suffering from clinical depression than those living in more comfortable economic circumstances (Lynch et al: 1997). Amongst adults of working age, research has found that mothers living in poverty are particularly vulnerable to mental ill health, the vulnerability of this group of women increases when material deprivation is combined with low social and personal support (Baker & Taylor: 1997: Hobcraft & Kiernan: 1999; Maughan and Lindelow, 1997).

6.4. Social security benefits are the major form of financial support for over 75% of UK adults of working age who find themselves faced with mental health problems for short, long or recurring periods of their lives. (Labour Force Survey: 2002).

6.5. A range of benefits relating to income, mobility, care and housing may be relevant to individuals with mental health problems. The current system is not flexible enough to meet the income needs of people whose mental health condition varies over time. Citizen Advice in Britain raised a number of concerns about the inadequacies of the medical assessment system in research published in 2005. The assessment of incapacity and disability in the benefit system poses particular problems for people with mental health problems (Davis & Betteridge: 1997; Hirst & Sainsbury: 1996; Sainsbury: 1995). The interaction between income related and non-income related benefits is also an issue that is not fully recognised by Government policy in this area.

6.6. Evidence suggests that while people with mental health problems who claim benefits face many of the same difficulties as other claimants, they are disproportionately affected by the complexities of the benefits system. (Bird et al: 2001). Each benefit claim made requires the completion of lengthy forms at regular intervals, to establish eligibility, the production of evidence to support each claim and the submission of additional information about changes in circumstances. The focus, investment of time and energy required by these procedures is considerable.

6.7. People with mental health problems when asked to describe some of the common physical and behavioural effects of having a diagnosed mental illness mention - lack of motivation and interest; fear of making contact with people and leaving home; paranoia, feelings of hopelessness and despondency; problems of concentration, confusion, permanent feelings of anxiety and worry (Ritchie et al: 1988). People with mental health problems with these common behaviours find it difficult to meet the ongoing claiming requirements of the benefits system.

6.8. The evidence of the under-claiming of benefits by adults with mental health problems from UK studies and initiatives demonstrates one of the negative outcomes of the lack of accessible information, advice and support (Keenan: 1995; Matthew Trust: 1997; Pacitti & Dimmick: 1996). The factors which contribute to this situation include the low priority given to this area of work by mental health and benefit agencies (Bird et al: 1998; Sharpe & Bostock: 2002) and staff in mainstream advice and benefit agencies experiencing difficulties in understanding and communicating with people with mental health problems (Bird et al: 1998; Regnier: 1996). 'Advice in Mind' produced by Citizen Advice Northern Ireland in 2005 illustrated the need for and importance of people with mental health problems getting access to good quality advice.

6.9. User based evidence from national and local survey work testifies to the discrimination, trauma and exclusion experienced by users in contact with such agencies (Beresford et al: 2000; Davis & Betteridge: 1990; Dunn: 1999).

6.10. The fluctuating nature of mental health conditions, the changing use of hospital and community based services and life changes can destabilise the security of the weekly benefit income paid to people with mental health problems.

6.11. Evidence of the financial exclusion of people with mental health problems can be found in the reports and campaigns of advice, legal and national mental health charities as well as surveys of user experiences. For example, a 1996 survey of mental health individuals found that 25% of users had had the experience of being turned down by a finance or insurance company. Evidence submitted to the 1999 MIND Inquiry into social exclusion and mental health problems led the inquiry panel to state that lack of access to banking services is a common problem for mental health individuals, and a key determinant in social exclusion.

6.12. People with mental health diagnoses report problems in obtaining insurance cover for a range of items including motor, life, travel, payment protection and health insurance (MIND: 2000). It appears to be common practice in the insurance industry to either refuse cover where the consumer is known to have a mental health problem or to ask people with mental health problems to pay increased premiums (ABI: 2001; Marks: 2003; MIND: 2000).

6.13. In addition, some people with mental health problems who do have insurance report difficulties in getting insurance companies to make payments in situations where mental ill health is seen to be a factor. Evidence from advice agencies and mental health organisations suggest that this response can affect a range of life areas e.g., being unable to claim payment protection designed to help consumers meet their credit and loans commitments when they experience an unexpected reduction in or loss of income due to ill health or redundancy, or being unable to draw on insurance to cover mortgage payments when income is lost.

6.14. The current strategy for social security is 'work for those who can, security for those who cannot'. As a result, a considerable effort has been put into encouraging the long-term sick and disabled back into work, but the current strategy contains an element of compulsion. People on Incapacity Benefit who fail to attend interviews can be penalised by loss of benefit or incapacity status. This fails to acknowledge the pressure having to attend such interviews can cause for someone with a severe mental illness.

6.15. Medical assessment is a regular feature of establishing and retaining entitlement to key disability benefits (notably Incapacity Benefit and Disability Living Allowance) and the quality of such assessments has been subject to significant scrutiny. Rushed assessments, lack of knowledge of mental health problems, disbelief of claimants, a disregard of specialist evidence and cultural insensitivity are not uncommon experiences. A report on the Social Security Agency's Medical Referee Service by the Advice Services Alliance in 2002 was also critical of the quality of assessment and sensitivity of some doctors. The Social Security Agency (Northern Ireland) has recently announced a review of the Medical Referee Service. This could usefully lead to greater use of occupational nurses and mental health specialists (medical and non-medical). This review was suspended and never completed.

Easing the Transition to Work

6.16. People with mental health problems who have been on benefit for long periods often need intensive support to get back to work. The current social security system does not allow for a continuum that would enable a person to move gradually through voluntary work to part-time work and full-time work or to stay at one level for a prolonged period if appropriate. The Government has improved flexibility within the Social Security system to encourage a return to work, but the current arrangements are complex, fragmented and not easily understood by claimants. An understanding of the arrangements requires extensive knowledge of social security and concerns have been raised that a move into training or work triggers a review on the assumption that a person's condition has improved. This is a disincentive to rehabilitation through work or training.

6.17. Improvements have been made to claim forms in recent years, but there is a considerable way to go. The claim form for disability living allowance remains complex and significantly oriented towards physical impairments. The claim form for Incapacity Benefit has an open question about mental health with no guidance as to the information required.

6.18. The Social Security Agency is moving towards providing greater support to assist with claims for disability benefits. It has also worked with the voluntary sector to look at ways of enhancing its customer service to particular groups (for example, physically disabled people and ethnic minorities). A similar exercise working with voluntary sector and other interested parties to examine customer service issues for people with mental health problems would be a welcome development.

6.19. There is a need to ensure that all those involved in frontline benefit administration and decision-making receive mental health awareness training that incorporates interaction with people with mental health problems. This also applies to the Medical Referee Service personnel, as well as chairpersons and members of The Appeals Service (NI). People with mental health problems should have access to an independent dedicated advice and advocacy service to deal with social security problems.

Qualitative Survey of Users and Carers

6.20. The Qualitative Survey of users and carers in a number of voluntary organisations in Northern Ireland identified a lack of competence of some Social Security staff in recognising customers with mental health problems.

6.21. There was no specific training for staff dealing with people with mental health problems or a learning disability.

6.22. Users identified difficulties with complex benefit forms and of understanding the complex legislation of benefit entitlement.

Where are we now?

6.23. The Social Security Agency provides a number of benefits including Disability Living Allowance, Attendance Allowance, Incapacity Benefit, Carers Allowance, Income Support, Pension Credit and Social Fund payments.

6.24. The Social Security Agency provides a Disability and Carers Service, which provides improvements to make services more accessible including provision of Disability Benefit Advisers. This pilot is ongoing, providing outreach service and taking an holistic approach to providing information and advice on benefits.

6.25. The Social Security Agency's Incapacity Benefits Branch has a Customer Care Team, which can deal with the needs of different customers. The Agency also provides awareness sessions in special schools and presentations to healthcare professionals.

6.26. The Social Security Agency has created a Direct Payment information booklet, produced in partnership with Mencap.

6.27. Jobs and Benefits Offices have Disablement Employment Advisers and Social Security Offices have Customer Enquiry Teams.

Recommendations

12. Independent advice and advocacy services should be embedded in mental health and learning disability services to help support and enable people with mental health problems or a learning disability to live independently with dignity and a good quality of life, both in and out of work.

13. There should be partnership schemes between Government, commercial companies, housing associations and credit unions to extend insurance cover and other financial products and services to financially excluded people with mental health problems or a learning disability.

14. The Social Security Agency should work with the voluntary sector and other relevant organisations to examine customer service issues for people with mental health problems and/or learning disability.

15. Social Security Agency decision-makers, Medical Referee staff, front line benefit staff and the Appeals Service (NI) chairpersons and tribunal members should receive more in-depth mental health and learning disability awareness training.

16. Financial institutions should review their policies to ensure that they treat people with mental health problems or learning disabilities no less favourably than they treat others in order to comply with the Disability Discrimination Act 1995.

7. EDUCATION

Background

7.1. Education and Library Boards (ELBs) and Boards of Governors of schools have a statutory responsibility to make special educational provision for pupils/children who have Special Educational Needs (SEN). A child has Special Educational Needs as defined in the Education (Northern Ireland) Order 1996 if he/she has a learning difficulty which calls for special educational provision to be made. The Order goes on to define 'learning difficulty' as meaning a child who:

a). Has a significantly greater difficulty in learning than the majority of children of his/her age.
b). Has a disability which either prevents or hinders him/her from making use of educational facilities of a kind generally provided for children of his/her age in ordinary schools.
c). Has not attained the lower limit of compulsory school age and is, or would be if special educational provision were not made for him/her, likely to fall within a) or b) above when he/she is of compulsory school age.

7.2. Actual provision will depend upon the individual needs of the pupil/child and can be made in a variety of settings ranging from mainstream schools, special units attached to mainstream schools or special schools and in some cases in the home. Again the 1996 Order defines the term 'special educational provision' as:

a). In relation to a child who has attained the age of two years, educational provision which is additional to, or otherwise different from, the educational provision made generally for children of his/her age in ordinary schools

b). In relation to a child under that age, educational provision of any kind. The ELBs have a statutory power to make special educational provision for children with Statements of Special Educational Needs, in order to meet the individual needs of the child. ELBs are responsible for the decisions about making, maintaining and ceasing to maintain Statements. There is a statutory right of appeal to the Special Educational Needs and Disability Tribunal about ELB statementing decisions.

7.3. According to the 2004 Annual Census of Schools, there are some 25,646 pupils with learning difficulties on SEN Registers. In terms of inclusion, and looking at the full range of pupils with SEN, there are 63% of pupils with Statements in mainstream classes or units. This figure has increased from 39% in 2000.

7.4. In order to effectively meet the SENs of pupils with a learning disability or mental health problems, strong partnerships between the health and education sectors are required. Those pupils with a learning disability require both tailored educational input and input from a range of Allied Health Professionals (AHP). There are existing pressures on the provision of AHP services to meet the needs of pupils in special schools or unit settings. It could be anticipated that pressures might increase in future years, as both the number and percentage of SEN pupils educated in mainstream settings increases in light of the greater emphasis on the right to mainstream education as a result of the Special Educational Needs and Disability Order 2005 (SENDO).

7.5. For pupils with mental health problems, support from mental health professionals is vital in order to sustain school placements, in whatever sector and to provide support for teachers as well as pupils.

7.6. Education and training relates to activities compatible with both vocational outcomes and personal development.

7.7. Effective links to voluntary work and organisations such as Further Education Colleges, Educational Guidance Service for Adults and the various job brokers and training organisations will expand the opportunities for people with severe mental health problems.

7.8. Some individuals will require considerable support in order to access mainstream services. Supported education initiatives for employment or leisure services have been shown to be effective in relation to health gains for people with more enduring mental health problems. The key worker should maintain overall responsibility for the client with the health services taking the lead in providing and promoting employment opportunities. Studies have emphasised that the positive effects of participating in college activity i.e., having structure to day, gaining strengths and skills, developing self identity and social inclusion need to be balanced with possible negative effects. Sensitive, needs-led, flexible support must be maintained to reduce anxiety and alleviate barriers to engagement.

7.9. Assessment of an individual's occupational performance, exploration of vocational goals and networking with local service providers is currently being performed by many Community Mental Health Teams (CMHT) within Northern Ireland. However, many teams do not have access to OT expertise or when present in teams they are engaged in generic work due to high caseload numbers amongst multi-disciplinary team members.

7.10. There is scope for development of opportunities for men and women with a learning disability within Further Education (FE) in Northern Ireland.

- Significant variation exists across colleges in the number of students with a learning disability enrolled as a proportion of the student body ranging from 1% - 13% in 2002. (Department for Employment and Learning 2002, FSER Snapshots)
- Average level of enrolments appears to be lower in Northern Ireland, 4.1% in 1999, as compared with 5.7% in England.
- The number of students enrolled on full-time courses is also lower, 32% in 2002 in Northern Ireland (ranging from 10% to 67% across the Colleges) as compared with 45% in England in 1999. (Department for Employment and Learning)
- Concerns exist about the lack of progression from FE provision; students not able to gain accredited awards from their study; the lack of links with job training and work experience; students repeating the same course content in subsequent years.

- It is encouraging that studies in Northern Ireland have highlighted a range of initiatives that are affording positive opportunities for young people with a learning disability to be involved in activities within the FE sector. This provision points the way towards the positive outcomes that might be achieved if such opportunities were more widespread and consistently available.

Qualitative Survey of Users and Carers

7.11. The Qualitative Survey of users and carers in a number of voluntary organisations in Northern Ireland identified the following issues:

- Teachers not well equipped to deal with emotional and mental well-being issues.
- Lack of awareness by children (e.g. bullying by children of other children with a relative who has mental health problems).
- Falling behind in education because of mental health problems.
- For pupils, physical education is compulsory, but not education in emotional and mental well-being.
- No systems or procedures in place for dealing with people with a mental health problems.
- Difficulty in obtaining and waiting time for assessments (although with statutory assessments, ELBs have a period of 26 weeks, subject to certain exclusions, to produce a final Statement, non-statutory assessments are subject to resources being available).
- Private psychological assessments not allowed. (While private assessments are allowed, they are not allowed to access provision earlier than would have ordinarily been the case.)
- Availability of concessions regarding transfer test.
- Additional stress caused by the transfer test.
- Lack of counsellors.
- Extremely difficult to access mainstream education for children with learning disabilities (e.g. the Independent Panel for Special Educational Advice, a voluntary organisation exists with the sole purpose of assisting parents' access mainstream education).
- Teacher resistance of children with mental health problems or learning disabilities, believed to be because of resources and performance tables, although DE does not actually publish performance tables.
- Mainstream access to education does not always allow access to schools' summer schemes.
- Need to fight for access to nursery, primary and secondary school.

Where are we now?

7.12. There has been a presumption to mainstream education for children with special educational needs for many years within the existing special education framework. This is subject to certain qualifications which relate to parents' wishes, the efficient education of other children, the efficient use of resources and the meeting of the SENs. The Education (NI) Order 1996 strengthened this presumption, and the more recent Special Educational Needs and Disability (NI) Order 2005 (SENDO) legislation provides further rights for children with special educational needs or disabilities.

7.13. The Department of Education and the Education and Training Inspectorate have undertaken a review of the role of the special school of the future. The report includes commentary on how special schools can help support teachers and pupils in mainstream schools, via outreach services. The Department of Education's policy on inclusion is that a continuum of SEN provision will be mainstreamed across the school sector. There are no plans to close special schools, but it is anticipated that the number of SEN pupils in mainstream schools will continue to grow following the implementation of the SENDO.

7.14. The SENDO became effective on 1st September 2005. It strengthens the existing presumption to inclusion. Some of the key features of the legislation include:

- Strengthening of the right to a mainstream school place for children with a statement, unless it is against the wishes of the parents or is incompatible with the efficient education of others.
- Education and Library Boards will provide an Information and Advice Service on SEN matters to parents of children with SEN in the area. This includes the establishment of a new, accessible website which provides a broad range of information on SEN.
- Education and Library Boards provide a new Dispute Avoidance and Resolution Service (DARS) to attempt to resolve disputes between parents and schools and parents and Boards.
- Responsible Bodies of schools and relevant Nursery providers are able to request a statutory assessment or re-assessment of the SEN of one of their pupils.
- Parents have increased rights of appeal to the Special Educational Needs and Disability Tribunal when the Education and Library Board makes an assessment of SEN. Education and Library Boards must maintain statements until the outcome of an appeal is known.
- All schools will be prohibited from discriminating against children who have disabilities in their admissions arrangements, in the education and associated services provided by the school and in relation to expulsions and suspensions from the school.
- Education and Library Boards are subject to more clearly defined timeframes for the drafting of Statements.
- All schools will be prohibited from discriminating against children who have disabilities in their admissions arrangements, in the education and associated services provided by the school and in relation to expulsions and suspensions from the school.
- Schools have to take reasonable steps to ensure pupils who have a disability are not placed at substantial disadvantage, in comparison to pupils who do not have a disability, in relation to the education and associated services provided to them.
- Education and Library Boards have to produce an 'accessibility strategy' to increase accessibility to the curriculum and school premises.
- Education and Library Boards have to improve the delivery of information, which is provided in writing for pupils who do not have a disability, to pupils who have a

disability, in ways that are determined after taking account of the effects of the disabilities and any preferences expressed by the pupil or their parents.

- Schools have to produce and keep under review disability accessibility plans and will have to publish information about their plans in their annual Board of Governors report.
- Education and Library Boards have a duty not to discriminate against a person or prospective pupil with a disability in carrying out their functions under various Orders relating to education.
- The Special Educational Needs Tribunal (SENT) has been restructured to become the Special Educational Needs and Disability Tribunal (SENDIST) and now hears claims against disability discrimination by schools and ELBs, as well as appeals against the special educational provision made by ELBS.

7.15 The Department of Education (DE) has reviewed to its Code of Practice on the Identification and Assessment of Special Educational Needs as a result of the new provisions of SENDO. After consultation, a new statutory Supplement to the Code was completed and became effective on 1st September 2005. This Supplement provides user-friendly guidance on the new SENDO provisions and offers additional guidance to schools and ELBs on inclusion in general.

7.16 DE is currently working on a new Parents' Guide to enable parents and carers of children with SEN to gain a better understanding of the new legal framework and where to access help and support.

7.17 In addition the Equality Commission for Northern Ireland, on behalf of DE, has developed a new Disability Discrimination Code of Practice for Schools. This gives clear guidance on the new disability duties introduced by the SENDO and examples of how schools and Boards can make reasonable adjustments in school settings for children with disabilities.

7.18 DE has recently produced (January 2006) a Report of the Transitions Inter Departmental Group, which includes an Action Plan to address shortcomings in the transition process for young people with Statements of SEN. The ELBS have the statutory lead role in the transitions planning process for statemented children. The Action Plan clearly sets out actions already taken by the three Departments concerned – The Department of Education, the Department of Health, Social Services and Public Safety and the Department for Employment and Learning (DEL). The actions already taken include a restructuring of the Careers Service by DEL to better support the transitions process, additional funding from DE to ELBs for dedicated Education Transitions Coordinators, across NI, to support the young person and the parent at this stage and to enable improvements to work experience opportunities and life skills training for young people, while still at school.

7.19 The Children and Young People's Funding Package provided £0.9m recurrent funding for additional places, for young people with statements of Special Education Need, on transition from school settings into the community. DHSSPS has agreed with representatives from the 4 Health and Social Services Boards that 150 purposeful places will be created in the community with voluntary organisations.

7.20 In addition the Children and Young People's Funding Package has provide an additional £0.1m for young people with statements of special educational need to improve their life chances through enhanced life skills packages before leaving school. This is on top of a further £0.1m mainstream funding for the same purpose.

Recommendations

17. Education and Library Boards should continue to develop their policies and services to provide support to children with mental health problems or a learning disability to enable them to receive the most appropriate education.

18. Education and Health and Social Services bodies should continue to collaborate to ensure that all the needs of children with a mental health problem or a learning disability are met.

19. Schools should be pro-active in identifying pupils with possible learning disabilities or mental health problems and in getting professional help. Where that help needs to be provided by Health and Social Services, a timely response should be provided.

20. Schools and Health and Social Care providers should make arrangements to ensure that, as far as possible, a child's education is not allowed to suffer during an episode of mental health problems including people with a learning disability.

21. The principle of equal access to the full life of the school should be pursued by statutory and voluntary organisations.

8 HEALTH AND SOCIAL CARE

Background

8.1. There is a range of specialist health and social services designed to meet the particular needs of people with mental health problems or a learning disability both in the community and in specialist hospital units. The Mental Health Programme of Care in Northern Ireland represents about 8% of Health and Social Care spend (2003/2004) and the Learning Disability programme about 8%.

8.2. Other reports from the Bamford Review of Mental Health and Learning Disability (NI) have examined these specialist services in detail and making recommendations for improvements. The key challenge for mental health and learning disability services is reform and modernisation, in particular developing community mental health and learning disability provision to prevent inappropriate admissions and re-admissions to hospital, and focusing hospital services on short-term assessment and acute treatment only.

8.3. However, there is evidence that people with a mental health problem or a learning disability do not have the same access to general health services as other members of the public.

8.4. The same issue arises elsewhere. The Disability Rights Commission published (September 2006) a report of its investigation into health inequalities experienced by people with mental health problems or a learning disability in England and Wales. The report highlights the scale of inequalities, which is described as "overwhelming" and calls for action on a range of fronts. Many of the findings could apply equally in Northern Ireland.

8.5. People with mental health problems are at increased risk of having physical health problems. Many deaths of people with more complex and enduring mental disorder are potentially preventable by better medical treatment and attention to lifestyle, including diet and smoking. Assessment of the needs of those with mental health problems should cover physical health needs. One approach to identifying and targeting appropriate information and services to people with more severe and enduring mental health needs is the establishment of case registers at primary care level (Barr and Cotterill 1999). Primary and secondary care services, in conjunction with the service user, should jointly identify which service will take responsibility for monitoring physical health.

8.6. General Practitioners should consider the health promotion of people with severe mental health problems within their practice and regularly monitor their physical health. The NICE Guidelines for Schizophrenia recommend paying particular attention to endocrine disorders such as diabetes and hyperprolactanaemia, cardiovascular risk factors, side-effects of medication and lifestyle factors such as smoking (NICE 2002).

8.7. The prevalence of smoking is far greater among those with mental health problems than in the general population and smokers with mental health problems tend to smoke more heavily than others. Mental health professionals tend not to raise the issue of smoking with people they come in contact with. These professionals however are well placed to offer advice and support on smoking cessation. Smoking is addressed as part of the Bamford Review report on Alcohol and Substance Misuse, which makes a number of recommendations in this area.

8.8. While life expectancy of people with a learning disability has improved over the last 60 years, mortality rates are still higher than in the general population. Some people are at higher risk of physical ill health arising from problems associated with particular conditions and healthcare professionals need to be aware of these.

8.9. There are however more basic healthcare needs which are often neglected in relation to people with a learning disability. Accessibility of information and advice on healthy lifestyles, uptake of screening programmes and other routine physical health checks. Access to appropriate dental treatment is a particular issue for many people with a learning disability. These problems are documented more fully in Equal Lives, the Bamford report on learning disability, and that report makes a range of recommendations for improvement.

8.10. The Bamford review's report on Alcohol and Substance Misuse recognises that, as more people with a learning disability are living in the community, they may be exposed to greater social stressors leading to increased use of alcohol and drugs as a coping mechanism. People with a learning disability may also see use of alcohol and drugs as a way of fitting in with their peers. Again the Bamford report on Alcohol and Substance Misuse makes a number of recommendations relating to this issue.

8.11. There are concerns regarding the lack of Child and Adolescent Mental Health Services, especially in terms of inpatient beds. Work has started on implementing the recommendations contained in the Bamford review's report "Vision of a Comprehensive Child and Adolescent Mental Health Service ".

8.12. A growing concern is the number of local suicides and the rising level of self-harm, mainly by young people. To address these concerns a Taskforce was established in July 2005 to develop a regional suicide prevention strategy. Following an extensive engagement and consultation process the final Strategy, "Protect Life – A Shared Vision", was published on 30 October 2006. The Strategy aims to tackle the issues of suicide and self-harm by taking a dual population and targeted approach. The Strategy recognises the fact that, while its primary focus is clearly on prevention, the achievement of its aims will be greatly influenced by the need for its implementation to be taken forward in parallel with progress being made on the delivery of the Promoting Mental Health Strategy and the Bamford Review of Mental Health and Learning Disability.

Qualitative Survey of Users and Carers

8.13. The Qualitative Survey of users and carers in a number of voluntary organisations in Northern Ireland identified the following issues:

- That GPs require better training in mental health issues.
- A relapse/deterioration in service users' mental health can result in a lack of motivation and drive to attend appointments.

- A negative impact of medication can cause weight problems, which becomes a secondary issue having a further negative impact on their mental health.
- Smoking alleviates some of the tensions resulting from mental health problems. Government no-smoking policy needs to consider 'outdoor' spaces for clients to smoke.
- Carers are often unable to attend hospital, dentist and eye care appointments, due to their caring role.

8.14. Issues raised in the review reports from people with a learning disability and their carers included:

- General health professionals not having an understanding of how to deal with people with a learning disability and not taking time to listen to them.
- Waiting times for dental treatment for people with a learning disability.

Where are we now?

8.15. The Investing for Health Strategy launched in March 2002 sets out the Executive's views on how the health and well-being of all the people here can be improved, and how the unacceptable inequalities in health can be reduced. Boards and Trusts are implementing this strategy through Health Improvement Plans, adopting a proactive, holistic approach that protects and improve health by implementing action plans being produced in a range of areas, including drugs and alcohol misuse and mental health promotion.

8.16. In recognition of the fact that children with learning disabilities are not receiving the necessary dental care and that there are long waiting lists, some of the funding made available from the Children and Young People's Funding Package is being used by the 4 Health Boards to address the waiting lists of children with learning disabilities who are waiting to receive dental treatment.

Recommendations

22. The health and social care needs of people with a learning disability or severe mental health problems need to be identified both at primary care and secondary care level.

23. Any assessment of the needs of people with a learning disability or with more complex mental health needs must include assessment of their physical health needs.

24. The Department of Health, Social Services and Public Safety should produce a Regional Framework for Health Improvement of people with a mental health problem or a learning disability, providing clear direction including targets and timescales. Each HSS Board should review their Health Improvement Plans to ensure that they translate the regional framework at a local level to support improved health outcomes for people with a mental health problem or a learning disability.

25. All generically trained health and social services professionals should receive awareness training on mental health and learning disability issues.

9 SOCIAL LIFE

Background

9.1. Mental well-being has been defined as the emotional and spiritual resilience which enables us to survive pain, disappointment and sadness. It is a positive sense of well-being and an underlying belief in our own dignity and worth.

9.2. A person's social connectedness – activities, relationships, interests, networks – has a significant impact on mental well-being and self-esteem. The reactions of others are often influenced in our social life, our activities, interactions, and our social self. Becoming mentally unwell can profoundly affect both our own social interactions and the reactions of others. It is in such situations that the experience of ignorance, fear and stigma can bring a new dimension of distress to the sufferer.

9.3. Mental health problems and the accompanying distress can affect all aspects of one's social life and relationships - within the family, with friends, with work colleagues. The sense of feeling isolated and stigmatised is a very real experience of many sufferers. There is also a sense of disempowerment and the distress arising from this – "my life will never be the same again". Acknowledgement of these issues and concerns can be of particular importance in promotion of recovery and needs to be recognised by professionals.

9.4. The issue of bullying that is commonly reported by advocates can also cause extreme distress and lead to isolation and social exclusion. This issue needs to be proactively addressed both in specialist services and the wider community. People with disabilities should be encouraged to exercise their rights to make complaints to the police or other relevant authority. The Criminal Justice (No. 2) (Northern Ireland) Order 2004 provides protection in that Article 3 extends the protections of Part III of the Public Order (Northern Ireland) Order 1987 to include groups defined by reference to sexual orientation or disability. (Part III currently provides offences and penalties against the use of threatening, abusive or insulting words or behaviour, the display and distribution of written material, and related activities intended or likely to stir up hatred or arouse fear).

9.5. The protections, currently provided with regard to religious belief, colour, race, nationality, ethnic or national origins, are extended by Article 3 to include sexual orientation and disability (including mental health problems and learning disabilities). The penalties for stirring up hatred or arousing fear in such cases is: on summary conviction, a maximum of 6 months imprisonment, a fine not exceeding the statutory maximum, or both; on conviction on indictment, a maximum of 2 years imprisonment, a fine, or both.

9.6. The relationship between service providers and individuals is of considerable importance in building and maintaining self-esteem, hope and self-worth for individuals with severe episodes of mental illness, experiencing loss of insight, loss of control, in addition to the painful experience of the symptoms of mental illness. This relationship can also provide a role model for family members who themselves may be bewildered and distressed through the experience of an illness episode. The engagement and empowerment of family members can greatly assist in the recovery and re-engagement of the individual in their social life and relationships.

9.7. Access to information has generally been experienced as a problem for individuals in mental health services. It is often difficult to get clear information and this lack of clarity is a problem for users, family and friends. The failure to convey relevant information clearly and in simple terms can cause distress to the user and their families. Information is required about services, choice of services, specific interventions including, for example, medication side effects and crisis arrangements.

9.8. In the situation of involuntary admission clarity takes on even greater importance. The sufferer in such situations often experiences a significant intrusion into their personal and family privacy. Involuntary admission procedures should be clearly explained and all involved should identify themselves to the sufferer, family and friends. Difficulties for the user in understanding information at such times requires professionals to pay even greater attention to communication and information sharing.

9.9. Within a multi-cultural society, the individual's specific cultural, spiritual and religious needs must be recognised and acknowledged. With the emphasis on community based care and treatment, the religious and spiritual dimension of an individual's life should be considered as part of holistic assessment.

9.10. Spirituality, described as "linking the deeply personal with the universal", is inclusive and unifying. In healthcare, spirituality is identified with experiencing a deep-seated sense of meaning and purpose in life, together with a sense of belonging. It is about acceptance, integration and wholeness.

9.11. The Royal College of Psychiatrists' leaflet on Spirituality and Mental Health states that service users have identified the following benefits of good quality spiritual care:

- Improved self-control, self-esteem and confidence.
- Speedier and easier recovery, achieved through both promoting the healthy grieving of loss and maximising personal potential.
- Improved relationships - with self, others and with God/creation/nature.
- A new sense of meaning, resulting in reawakening of hope and peace of mind, enabling people to accept and live with problems not yet resolved.

9.12. From a user perspective, spirituality can be an important part of one's personal life and in times of crisis a major source of sustenance. This can be of particular importance in situations where admission to hospital is required with the inevitable separation from family, friends and one's local community. It is a common user experience when in hospital that religious and spiritual needs are not adequately met. Service providers need to be sensitive to the spiritual needs of individuals at such times. It is important that staff working with people with mental health problems or learning disability encourage any helpful inner personal resources and explore what external supports from the community and/or faith tradition are available.

9.13. Available and affordable transport is a key requirement of a good social life. The introduction by the Department for Regional Development of reduced charges on public transport for people with a learning disability is a welcome development.

9.14. People with a learning disability often express dissatisfaction the lack of public transport and the prohibitive costs of taxis, problems with physical access to premises such as cinemas, nightclubs, bars and restaurants and the lack of a companion – a befriender – to accompany them.

9.15. Provision of transport within Health and Social Services day services consumes over 25% of the total budget. As a consequence of the locations of many day centres, individuals can spend very lengthy periods being transported to/from centres with only 20% of centres able to transport most of their attendees from home to centre in less than 30 minutes.

9.16. A number of services have developed innovative independent travel training schemes, which have increased the capacity of individuals to make fuller use of public transport.

9.17. Many people with a learning disability live lonely lives. Most of their free time is spent in home-based pursuits such as watching television and listening to music with few friends of their own age. In a study in 2003, the researchers interviewed the parents of over 50 school-leavers from 2 special schools for pupils with severe learning disabilities in Northern Ireland. Three in five of the young people (58%) were reported to have no friends of their own. In all, 90% of parents would like their son or daughter to be more involved with friends of their own age and they mentioned the need for more clubs and for more sports and leisure activities.

9.18. A similar picture emerges for adults. In a 2002 study, over 2 in 5 people reported having no friends outside of the day centre they attended and 4 was the most that anyone reported. The most common activities undertaken with friends were going to discos and social clubs, but most of these were organised specifically for people with a learning disability.

9.19. A study of 65 persons resettled from a long-stay learning disability hospital in Northern Ireland into nursing home and residential care found that only 14 people (21%) had regular or frequent contact with friends outside of the residence.

9.20. Overall people with a learning disability tend to lead more sedentary lifestyles than the general population, performing significantly less than the minimum levels of physical activity recommended by the Department of Health. Levels of obesity appear to be rising among adults with a learning disability in Northern Ireland.

9.21. People with a learning disability often express dissatisfaction with their community, recreation and leisure activities. They mention in particular the need for more evening and weekend activities and greater opportunities to take part in community events.

9.22. Many family carers are also concerned about the lack of leisure opportunities. Among the suggestions they made were:

- Drop in centres and more social clubs.
- Weekend or short breaks away.
- Befriending schemes with long-term commitments.
- Education of the general public about learning disability.
- Community Access/Support Workers to allow individuals to attend events/concerts rather than depending on their ageing parents/carers to take them.
- Day centre facilities utilised in the evenings.
- Relatively little monies have been expended by social services in promoting the social and leisure lives of people with a learning disability. Often this has been left to charitable groups (often led by parents and relatives) and they continue to be the main provider of leisure opportunities outside working hours with a heavy reliance on volunteers.
- The main service innovations in this area have revolved around the concept of befrienders; ideally a person of similar age, background and interests recruited to share some of their leisure time with a chosen partner. A Northern Irish survey identified this as the fifth most popular form of voluntary activity with an estimated 80,000 people involved across all client groups.
- A range of agencies in Northern Ireland has set up a number of dedicated befriending schemes mostly in the non-statutory sector although as yet there has been no evaluation undertaken of their impact and sustainability.

9.23. Few resources are spent in encouraging access to social and leisure opportunities by people with mental health problems or a learning disability. Greater attention to developing people's social networks could pay dividends in other ways by reducing the possible consequences of social isolation including challenging behaviours and depression.

9.24. Meaningful relationships, including marriage, and expression of one's sexuality contribute greatly to people's quality of life. The sexual expression and developing sexuality of people with a learning disability is often seen as problematic and not a normal part of growth and development. This ignores the person's rights and the benefits to be gained.

9.25. The subject of relationships and sexuality and the social skills required in forming appropriate relationships receive insufficient attention at home, at school and in other service settings.

9.26. The changes in the life stages of people with a learning disability are often not recognised. There is a marked lack of sex education for men and women with a learning disability and lack of guidelines for staff who provide sex education.

9.27. Life stages and general sexual and reproductive health care is not provided. For women in particular issues are not adequately addressed in relation to premenstrual syndrome, cervical and breast screening, sexual health screening and the menopause.

9.28. Sexual orientation and preferences often go unnoticed and undetected or attributed to lack of experience, choice or environmental influences.

9.29. Staff members who participated in a consultation exercise highlighted a number of issues pertinent to supporting sexual expression that they feel unable to resolve because of lack of clear legislation, policy and guidelines. These included:

- Participants working in residential care settings who expressed feelings of frustration around being willing to support clients in their sexual expression but being hampered by how current legislation is interpreted and implemented through policy.
- A perceived need for greater clarity between the Mental Health (Northern Ireland) Order 1986, Sexual Offences Act 2003 and Human Rights Act 1998, in relation to individual's rights around sexual expression and the process used to assess capacity to consent.
- A need for ongoing training, supervision and support to develop understanding and competencies at different levels of intervention, mostly around inappropriate touch/abusive behaviours.
- Policies are now more likely to acknowledge the rights of people with a learning disability around their sexuality and sexual expression, however, there is a lack of clarity around whether individual's rights are prioritised above parents' rights and the legal position regarding parents' rights i.e. if there is a clash between the individual's wishes and parents' wishes, who should be prioritised?
- Balancing rights, responsibilities, vulnerabilities and risk in this area is complex and hampered by apparent lack of clear direction as to the parameters within which staff should work at a practice level, e.g., what kind of information staff should be giving relevant to their role if a man or woman with a learning disability asks for information about contraception or wanting to be sexually active.

9.30. There is a lack of support, education and training for parents, to enable them to identify emergent issues and gain knowledge and skills in supporting their children. Many parents struggle with their own values and beliefs around sexual expression and the desire of young people and adults with a learning disability to form sexual relationships. The following issues have been expressed by parents:

- Fears and concerns around lack of support for children particularly when during times of transition from primary to post primary education, where they are seeking to keep their children in mainstream education.
- Education around appropriate sexual expression. Parents often feel unable to discuss problems with others and are unable to identify appropriate means of support.
- Accessing affordable information to support them to do sex education work with their sons or daughters.

Recommendations

26. The limitations posed by existing transport provision have curtailed access to educational, employment and leisure opportunities. A determined effort is required to ensure that these barriers are removed. There is scope to more actively promote independent travel on public transport and on foot. This should be planned with the support of the family and must feature in schools and higher and further education establishments. In addition, those charged with responsibility for public transport must ensure that the particular needs of men and women with a learning disability are incorporated in their strategies.

27. Leisure and recreation schemes should be promoted and co-ordinated at District Council level. An audit should be commissioned of leisure and recreation facilities, societies and clubs within their area that serve the wider community as well as people with disabilities. This Directory should be maintained by District Councils and widely circulated to all service-providers (including residential services) and family carers. A central point should be created or identified for recruiting volunteer helpers and drivers. Different schemes within District Councils should have shared access to a minibus or people-carriers. Seed monies should be available to initiate new schemes.

28. Now that all services are expected to have policy guidelines in place on sexuality and personal relationships, there needs to be a concerted effort across all services to make available opportunities for education on these issues and on sexual health. This should be done with the knowledge and support of family carers, but they should not have a sanction on their relative's participation if that is his or her wish.

29. The issue of bullying that is commonly reported by self-advocates needs to be proactively addressed both in specialist services and the wider community.

30. The Office of the First Minister and Deputy First Minister should take a leadership role developing people's social networks with central and local Government, the voluntary and private sectors to help reduce social isolation.

10. WAY AHEAD

10.1 During the review it was noted that there is a lack of local research in Northern Ireland in promoting social inclusion for people with mental health problems or a learning disability.

10.2 Implementation of the recommendations will be the key to delivering social inclusion for people with mental health problems and/or a learning disability.

Recommendations

31. There is a need to gather further information on the social inclusion needs of people with mental health problems or a learning disability.

32. The inter-departmental taskforce needs to address the recommendations of this report by addressing the implementation issues including: an action plan, timetables, targets, resources, budgets, research, evaluation and monitoring.

CONCLUSION

11.1 Many people with a learning disability or a mental health problem have not always been included as full and equal members of society. The effective implementation of this Report's recommendations will help people with a learning disability or mental health problems to reach their full potential, as equal members of society.

Annex 1

MEMBERSHIP OF THE PROMOTING SOCIAL INCLUSION GROUP

The Promoting Social Inclusion (PSI) Group was established within the Social Justice and Citizenship Committee (which is part of the overall Bamford Review of Mental Health and Learning Disability), to take forward the review of social inclusion. Membership of the PSI group included representation from Office of the First and Deputy First Minister (OFMDFM), Department of Health Social Services and Public Safety (DHSSPS), Department for Social Development (DSD), Social Security Agency (SSA), Department for Employment and Learning (DEL), Department of Education (DE), Department for Regional Development (DRD), the Law Centre, the voluntary sector, carers and users.

Annex 2

QUALITATIVE SURVEY OF SERVICE USERS AND CARERS

The Qualitative Survey of Users and Carers was performed by DHSSPS. Two staff met with users affiliated to various mental health and learning disability voluntary organisations throughout the province in early 2004 to establish difficulties they had with social inclusion for people with a learning disability or mental health problems. The organisations visited were Newry and Mourne Mental Health Forum, Rethink, Aware Defeat Depression, S.T.E.E.R. and the Down's Syndrome Association.

Annex 3

RECOMMENDATIONS

1. There is an ongoing need to monitor negative stereotypes within the community and to change the attitudes that reinforce these negative stereotypes. Communities need to be educated to ensure the successful social inclusion of people with a mental health problem or a learning disability in their community.

2. There is a fundamental need for a campaign to challenge the images that communicate negative stereotypes. The campaign needs to directly involve people with first-hand experience of discrimination, target specific audiences and monitor and evaluate its effectiveness.

3. All service providers must be encouraged to provide information in a form that is understood by people with mental health problems or a learning disability.

4. There is a need to establish a group to address the stigma associated with mental health problems and learning disabilities.

5. The Labour Force Survey (2002) indicated that only 21% of people with a mental health problem or learning disability are in employment yet research from the US found that with effective rehabilitation support, up to 58 % of adults with severe and enduring mental health problems are able to work using the Individual Placement and Support approach. Therefore the Northern Ireland target should be at least 50% of people with mental health problems or a learning disability should be in full time employment.

6. Employment Advisors should work with community mental health teams and community learning disability teams to provide pathways to employment.

7. European monies have funded a number of supported employment positions and Departments should mainstream this funding, where it has been shown to achieve positive outcomes.

8. Permitted work rules for Incapacity Benefit and Severe Disablement Allowance should be further improved, simplified and promoted effectively to reduce the barrier from moving from benefit to work. Returning to work should be on a voluntary basis and people should not be disadvantaged if their condition changes and prevents them from continued working.

9. DSD and housing providers should develop a housing strategy to ensure people with mental health problems and learning disabilities can, where possible, live in the accommodation of their choice, subject to normal financial constraints.

10. People with mental health problems or learning disabilities should have the choice to live independently but the use of specialised group housing has a role to play, for example as step-down accommodation after leaving hospital.

11. DSD should ensure participation of people with mental health problems or a learning disability in the planning of housing services.

12. Independent advice and advocacy services should be embedded in mental health and learning disability services to help support and enable people with mental health problems or a learning disability to live independently with dignity and a good quality of life, both in and out of work.

13. There should be partnership schemes between Government, commercial companies, housing associations and credit unions to extend insurance cover and other financial products and services to financially excluded people with mental health problems or a learning disability.

14. The Social Security Agency should work with the voluntary sector and other relevant organisations to examine customer service issues for people with mental health problems and/or learning disability.

15. Social Security Agency decision-makers, Medical Referee staff, front line benefit staff and the Appeals Service (NI) chairpersons and tribunal members should receive more in-depth mental health and learning disability awareness training.

16. Financial institutions should review their policies to ensure that they treat people with mental health problems or learning disabilities no less favourably than they treat others in order to comply with the Disability Discrimination Act 1995.

17. Education and Library Boards should continue to develop their policies and services to provide support to children with mental health problems or a learning disability to enable them to receive the most appropriate education.

18. Education and Health and Social Services bodies should continue to collaborate to ensure that all the needs of children with a mental health problem or a learning disability are met.

19. Schools should be pro-active in identifying pupils with possible learning disabilities or mental health problems and in getting professional help. Where that help needs to be provided by Health and Social Services, a timely response should be provided.

20. Schools and Health and Social Care providers should make arrangements to ensure that, as far as possible, a child's education is not allowed to suffer during an episode of mental health problems including people with a learning disability.

21. The principle of equal access to the full life of the school should be pursued by statutory and voluntary organisations.

22. The health and social care needs of people with a learning disability or severe mental health problems need to be identified both at primary care and secondary care level.

23. Any assessment of the needs of people with a learning disability or with more complex mental health needs must include assessment of their physical health needs.

24. The Department of Health, Social Services and Public Safety should produce a Regional Framework for Health Improvement of people with a mental health problem or a learning disability, providing clear direction including targets and timescales. Each HSS Board should review their Health Improvement Plans to ensure that they translate the regional framework at a local level to support improved health outcomes for people with a mental health problem or a learning disability.

25. All generically trained health and social services professionals should receive awareness training on mental health and learning disability issues.

26. The limitations posed by existing transport provision have curtailed access to educational, employment and leisure opportunities. A determined effort is required to ensure that these barriers are removed. There is scope to more actively promote independent travel on public transport and on foot. This should be planned with the support of the family and must feature in schools and higher and further education establishments. In addition, those charged with responsibility for public transport must ensure that the particular needs of men and women with a learning disability are incorporated in their strategies.

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