Valuing People: A New Strategy for Learning Disability for the 21st Century

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Valuing People

A New Strategy for Learning Disability for the 21st Century

A White Paper

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CONTENTS

FOREWORD BY THE PRIME MINISTER

People with learning disabilities can lead full and rewarding lives as many already do. But others find themselves pushed to the margins of our society. And almost all encounter prejudice, bullying, insensitive treatment and discrimination at some time in their lives.

Such prejudice and discrimination – no less hurtful for often being unintentional – has a very damaging impact. It leads to your world becoming smaller, opportunities more limited, a withdrawal from wider society so time is spent only with family, carers or other people with learning disabilities.

What's also a real cause for concern and anxiety is that many parents of learning disabled children face difficulties in finding the right care, health services, education and leisure opportunities for their sons and daughters. At best, they can feel obstacles are constantly put in their way by society. At worst, they feel abandoned by the rest of us.

We have to change this situation if we are to achieve our goal of a modern society in which everyone is valued and has the chance to play their full part. There has been progress – often through the efforts of families, voluntary organisations and people with learning disabilities themselves. But a great deal more needs to be done.

This White Paper sets out this Government's commitment to improving the life chances of people with learning disabilities. It shows how we will meet this commitment by working closely with local councils, the health service, voluntary organisations and most importantly with people with learning disabilities and their families to provide new opportunities for those with learning disabilities to lead full and active lives.

I know the publication of a White Paper, however good its proposals, does not itself solve problems. The challenge for us all is to deliver the vision set out in this document so the lives of many thousands of people with learning disabilities will be brighter and more fulfilling. It is a challenge I am determined this Government will meet.

Tony Blair

EXECUTIVE SUMMARY

People with learning disabilities are amongst the most vulnerable and socially excluded in our society. Very few have jobs, live in their own homes or have choice over who cares for them. This needs to change: people with learning disabilities must no longer be marginalised or excluded. *Valuing People* sets out how the Government will provide new opportunities for children and adults with learning disabilities and their families to live full and independent lives as part of their local communities.

Where we are today

Problems and Challenges

There are about 210,000 people with severe learning disabilities in England, and about 1.2 million with a mild or moderate disability. Health and social services expenditure on services for adults with learning disabilities stands at around £3 billion. In the 30 years since the last White Paper *Better Services for the Mentally Handicapped*, progress has been made in closing large institutions and developing services in the community, but more needs to be done. There are major problems, including:

- Poorly co-ordinated services for **families with disabled children especially for those with severely disabled children;**
- Poor planning for **young disabled people at the point of transition into adulthood;**
- Insufficient support for **carers, particularly for those caring for people with complex needs;**
- People with learning disabilities often have little **choice or control** over many aspects of their lives;
- Substantial **health care** needs of people with learning disabilities are often unmet;
- **Housing choice** is limited;
- **Day services** are often not tailored to the needs and abilities of the individual;
- Limited opportunities for **employment;**

- The needs of **people from minority ethnic communities** are often overlooked;
- **Inconsistency in expenditure and service delivery**; and
- Few examples of real **partnership** between health and social care or involving people with learning disabilities and carers.

The New Vision

- Four key principles of **Rights**, **Independence**, **Choice**, **Inclusion** lie at the heart of the Government's proposals. Legislation which confers rights on all citizens, including the Human Rights Act 1998 and the Disability Discrimination Act 1995, applies equally to all people with learning disabilities, and the Disability Rights Commission will work for people with learning disabilities.
- New national objectives for services for people with learning disabilities, supported by new targets and performance indicators, to provide clear direction for local agencies
- A new **Learning Disability Development Fund of up to £50 million per annum from April 2002**: £20 million capital and up to £30 million revenue. The revenue element of the Development Fund will be created from within old long-stay health funding as it is released over time. The Development Fund will be targeted on the key priorities of the White Paper, including modernising day centres, enabling people to move from long-stay hospitals to more appropriate accommodation in the community, developing supported living approaches for people living with older carers, developing specialist local services for people with severe challenging behaviour and developing integrated facilities for children with severe disabilities and complex needs. The Development Fund will be made available subject to the condition that resources may only be used where they are deployed as pooled funds under the Health Act flexibilities.
- A new central **Implementation Support Fund of £2.3 million a year for the next 3 years** that will be used to fund a range of developments including advocacy and a new national information centre and help line.

Better life chances for people with learning disabilities

Disabled Children and Young People

- Learning disabled children and their families face many barriers to full participation in society. The Government's objective is to ensure that disabled children gain maximum life chance benefits from educational opportunities, health and social care while living with their families or in other appropriate settings.
- To achieve this we will ensure that learning disabled children and their families are an integral part of the Quality Protects programme, the Department for Education and Employment's Special Educational Needs Programme of Action and the Connexions Service. Disabled children will be a priority group under the Quality Protects programme with £60 million over the next three years earmarked to provide better support. The Schools Access Initiative will provide funds to improve accessibility of mainstream schools and the Standards Fund will be used to improve provision for children with special educational needs.
- Transition from childhood to adulthood can be a particularly difficult process for both disabled children and their parents/carers. Our objective is to ensure continuity of care and support and equality of opportunity for young people and their families so that as many learning disabled young people as possible take part in education, training, or employment. The Connexions Service will provide new help and advice to disabled young people as they move into adult life.

More Choice and Control for People with Learning Disabilities

- People with learning disabilities have little control over their lives, few receive direct payments, advocacy services are underdeveloped and people with learning disabilities are often not central to the planning process. The Government's objective is to enable people with learning disabilities to have as much choice and control as possible over their lives and the services and support they receive.

- To achieve this, we are investing at least **£1.3 million a year for the next 3 years to develop advocacy services** for people with learning disabilities in partnership with the voluntary sector. We are extending eligibility for direct payments through legislation. We will also set up a national forum for people with learning disabilities and enable them to benefit from the improvement and expansion of community equipment services now under way.
- A person-centred approach will be essential to deliver real change in the lives of people with learning disabilities. Person-centred planning provides a single, multi-agency mechanism for achieving this. The Government will issue new guidance on person-centred planning, and provide resources for implementation through the Learning Disability Development Fund.

Supporting Carers

- Caring for a family member with a learning disability is a lifelong commitment. Our objective is to increase the help and support carers receive from all local agencies in order to fulfil their family and caring roles effectively.
- To help carers, we are providing **£750,000 over the next three years to fund the development of a national learning disability information centre and helpline in partnership with Mencap**. We will implement the Carers and Disabled Children Act 2000. Councils will be encouraged to identify carers aged over 70 and those from minority ethnic communities. We will also ensure that carers and their organisations are represented on the Learning Disability Task Force.
- Carers will benefit from our package of extra help worth more than £500 million over 3 years, which the Government announced in the autumn of 2000. In April 2001, the carer premium in the income-related benefits will rise to £24.40 a week, and the Invalid Care Allowance (ICA) earnings limit will rise to £72 a week. As soon as the legislative programme allows, people aged 65 and over will be able to claim ICA and entitlement to ICA will continue for up to 8 weeks after the death of the disabled person, to allow carers time to adjust.

Improving Health For People With Learning Disabilities

- Many people with learning disabilities have greater health needs than the rest of the population. They are more likely to experience mental illness and are more prone to chronic health problems, epilepsy, and physical and sensory disabilities. The Government's objective is to enable people with learning disabilities to have access to a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard and with additional support where necessary.
- We will ensure that people with learning disabilities, including those from minority ethnic communities, have **the same right of access to mainstream health services** as the rest of the population. The NHS will promote equality for people with learning disabilities from minority ethnic communities in accordance with its new general duty in the Race Relations (Amendment) Act 2000, which comes into force on 2 April 2001. **Health facilitators** will be appointed from each local community learning disability team to support people with learning disabilities in getting the health care they need. We will ensure that all people with learning disabilities are **registered with a GP** and have their own **Health Action Plan**. There will be a new role for specialist learning disability services, focusing on making best use of their expertise.

Housing, Fulfilling Lives, and Employment

- **Housing**. People with learning disabilities and their families currently have few options about where they live. Our objective is to enable people with learning disabilities and their families to have greater choice and control over where and how they live. We are legislating to improve provision of advice and information by housing authorities, and will be issuing joint DH/DETR guidance on housing care and support options. We will complete the reprovision of the remaining long-stay hospitals to enable people still living there to move to more appropriate accommodation in the community by 2004.

- **Fulfilling Lives**. Our objective is to enable people with learning disabilities to lead full and purposeful lives in their communities and develop a range of activities including leisure interests, friendships and relationships. To achieve this, we will take forward a 5 year programme to modernise local councils' day services. The Learning and Skills Council will ensure equal access to education. We will outlaw discrimination against people with learning disabilities on public transport. Services for parents with a learning disability will be improved. Department of Social Security staff will receive disability awareness training to help them work with people with learning disabilities.
- **Employment**. Very few people with learning disabilities – probably less than 10% – have jobs. Our objective is to enable more people with learning disabilities to participate in all forms of employment, wherever possible in paid work, and to make a valued contribution to the world of work. We will develop **new targets for increasing numbers of people with learning disabilities in work** and ensure that the Workstep programme meets the needs of people with learning disabilities. There will be a study of the links between supported employment and day services. The Department of Social Security will ensure careful assessment of entitlement to Disability Living Allowance. Job Brokers under the New Deal for Disabled People will have the skills needed to work with people with learning disabilities.

Quality Services

- The Government is committed to raising standards and improving the quality of services for people with learning disabilities. Good quality services that promote independence, choice and inclusion will lead to good outcomes for people with learning disabilities. We will look to the Social Care Institute of Excellence to be a leading source of expertise. Local quality assurance frameworks for learning disability will be in place by April 2002. We will issue guidance on user surveys and on physical intervention. We are taking action to assist vulnerable or intimidated witnesses to give evidence in Court and so improve their access to justice.

- At present, most of the learning disability workforce is unqualified. The Government wants to see an appropriately trained and qualified workforce. Health and social care workforce strategies will provide new opportunities for learning disability staff. We will also introduce the **Learning Disability Awards Framework** from April 2001 which will provide a new route to qualification for care staff. We will also support a range of leadership initiatives through the Learning Disability Development Fund.
- Good quality services will provide the right care for people with additional or complex needs. This includes people with severe and profound disabilities, people with learning disabilities and epilepsy, those with learning disabilities and autism, people with challenging behaviour and older people with learning disabilities.

Delivering Change

Partnership Working

- Effective partnership working by all agencies is the key to achieving social inclusion for people with learning disabilities. To promote stronger local partnerships, we will build on existing joint planning structures to establish Learning Disability Partnership Boards within the framework of Local Strategic Partnerships by October 2001. Partnership Boards will be responsible for agreeing plans for the use of the Health Act flexibilities.

Making Change Happen

- Delivering these ambitious plans will take time and requires a long-term implementation programme. At national level, we will be investing new resources in 2001/02 to support implementation. We will:
- Set up a **Learning Disability Task Force** to advise the Government on implementation;
- Establish an **Implementation Support Team** to promote change at regional and local level;
- Fund a £2 million learning disability research initiative *People with Learning disabilities: Services, Inclusion and Partnership* from 2001/02;

- At a local level, Learning Disability Partnership Boards will have lead responsibility for ensuring implementation. They will need to develop local action plans by 31 January 2002 to supplement their learning disability Joint Investment Plans;
- The Social Services Inspectorate will carry out a national inspection of learning disability services in 2001/02.

PREFACE

> *'You should be proud of who you are' (Eve)*[1]

1 *Valuing People: A New Strategy for Learning Disability for the 21st Century* sets out the Government's proposals for improving the lives of people with learning disabilities and their families and carers, based on recognition of their rights as citizens, social inclusion in local communities, choice in their daily lives and real opportunities to be independent.

2 Developing these proposals involved extensive consultation over more than a year with key interests in the learning disability field:

- The Department of Health's national Learning Disability Advisory Group and the Service Users Advisory Group were consulted on emerging ideas;
- Six working groups bringing together people with learning disabilities, carers[2], local authority, NHS, and voluntary sector representatives, and researchers, as well as the key government departments, advised us on services for children, carers, health services, supporting independence, workforce training and planning, and building partnerships;
- Seven workshops across the country attended by almost 1,000 people, including people with learning disabilities and carers;
- Seminars on particular themes such as parents with learning disabilities, and consultation with disabled children were held to produce ideas for improving services;
- Other contributions came through our dedicated website (www.doh.gov.uk/learningdisabilities).

3 People with learning disabilities played an important part in the consultation process. Their contribution has been of central importance.

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[1] All the quotes are from people with learning disabilities came from the consultation process.

[2] The carers who helped us develop the new strategy prefer to describe themselves as 'family carer' because this emphasises the family relationship. The Department of Health uses the term 'carer' to describe people who are not paid for caring and 'care worker' for people who are paid to work as carers.

4 Clear messages emerged from this consultation:

- **Children with learning disabilities** want to be treated like other children, not always seen as "special", and to be included in ordinary activities;
- **Parents of disabled children** want better advice and information and an integrated approach from services. Their expectations are often disappointed;
- **People with learning disabilities** often feel excluded and unheard. They want to be fully part of our society, not marginalised or forgotten. They told us advocacy and direct payments were key to helping them gain greater independence and control;
- **People with severe learning disabilities and complex needs** are more likely to receive poor quality services;
- **Carers** feel strongly that they have a lifelong responsibility for their sons or daughters. They want to be treated as full partners by public agencies. They need better information and support.

Our new strategy shows how the Government will respond to these concerns.

5 We also commissioned three reports which are being published to accompany *Valuing People*:

- **Nothing about Us Without Us: the report from the Service Users Advisory Group:** For the first time, people with learning disabilities have played a direct part in formulating Government policy. The members of the Service Users Advisory Group conducted a series of visits to local groups of learning disabled people. Listening to what people with learning disabilities had to tell us about their lives has helped us understand the need for change.
- **Family Matters, Counting Families In:** The report from the family carers working group offers valuable insights into the reality of service provision based on lifelong experience of caring for someone with a learning disability.
- **Learning Difficulties and Ethnicity**,[3] by the Centre for Research in Primary Care, University of Leeds. People with learning disabilities from minority ethnic communities and their families are too often overlooked. Meeting their needs is essential to providing a good service.

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[3] The authors use the term 'learning difficulties' as this was the preferred term among user organisations and disability writers.

PART ONE:

WHERE WE ARE NOW

CHAPTER 1

PROBLEMS AND CHALLENGES

1.1 People with learning disabilities are amongst the most socially excluded and vulnerable groups in Britain today. Very few have jobs, live in their own homes or have real choice over who cares for them. Many have few friends outside their families and those paid to care for them. Their voices are rarely heard in public. This needs to change.

'It's about time we had something for ourselves' (Gary)

1.2 It is thirty years since the last White Paper on learning disability services *Better Services for the Mentally Handicapped*, was published. Our new agenda needs to be based on social inclusion, civil rights, choice and independence. People with learning disabilities have the right to be full members of the society in which they live, to choose where they live and what they do, and to be as independent as they wish to be.

1.3 Achieving this aim requires all parts of Government to work in partnership. Social care, health, education, employment, housing, leisure and social security all have a part to play, with local councils taking a lead to ensure that partnership becomes a reality at local level.

What is Learning Disability?

1.4 *Valuing People* is based on the premise that people with learning disabilities are people first. We focus throughout on what people can do, with support where necessary, rather than on what they cannot do.

1.5 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.

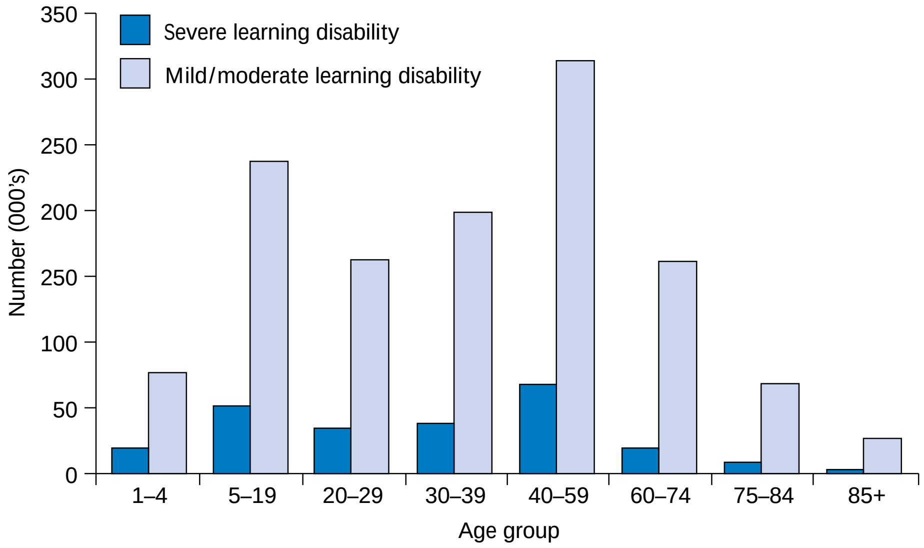
1.6 This definition encompasses people with a broad range of disabilities. The presence of a low intelligence quotient, for example an IQ below 70, is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. An assessment of social functioning and communication skills should also be taken into account when determining need. Many people with learning disabilities also have physical and/or sensory impairments. The definition covers adults with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder who may be of average or even above average intelligence – such as some people with Asperger's Syndrome. We consider the additional needs of people with learning disability and autism in more detail in Chapter 8.

1.7 'Learning disability' does not include all those who have a 'learning difficulty' which is more broadly defined in education legislation.

How many people have learning disabilities?

1.8 Producing precise information on the number of people with learning disabilities[4] in the population is difficult. In the case of people with severe and profound learning disabilities, we estimate there are about 210,000: around 65,000 children and young people, 120,000 adults of working age and 25,000 older people. In the case of people with mild/moderate learning disabilities, lower estimates suggest a prevalence rate of around 25 per 1000 population- some 1.2 million people in England.

Figure 1 – People with learning disabilities, 1999



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[4] People with severe learning disabilities are those who need significant help with daily living. People with mild/moderate learning disabilities will usually be able to live independently with support.

1.9 Prevalence of severe and profound learning disability is fairly uniformly distributed across the country and across socio-economic groups. Mild to moderate learning disability, however, has a link to poverty and rates are higher in deprived and urban areas. The number of people with severe and profound learning disabilities in some areas is affected by past funding and placement practices, especially the presence of old long-stay patients and people placed outside their original area of residence by funding authorities.

Future Numbers

1.10 Evidence suggests that the number of people with severe learning disabilities may increase by around 1% per annum for the next 15 years as a result of:

- increased life expectancy, especially among people with Down's syndrome;
- growing numbers of children and young people with complex and multiple disabilities who now survive into adulthood;
- a sharp rise in the reported numbers of school age children with autistic spectrum disorders, some of whom will have learning disabilities;
- greater prevalence among some minority ethnic populations of South Asian origin.

Developments Since 1971

1.11 Until the 1950s, it was generally accepted that people with learning disabilities could enjoy a better quality of life living with other disabled people in segregated institutions rather than in the community with their families. The terms "mental deficiency" and "mental sub-normality" reflected the underlying attitudes of the day. Until 1959 those who lived in long-stay institutions were detained under the Mental Deficiency Act. By the end of the 1960s it became clear that the quality of care in long-stay hospitals was often extremely poor. Parental pressure became an important influence in the drive for change. The 1970 Education Act ensured that education should be provided for all children, no matter how severe their disability.

1.12 The 1971 White Paper *Better Services for the Mentally Handicapped* paved the way for change. It set an agenda for the next two decades which focused on reducing the number of places in hospitals and increasing provision in the community. It committed the

Government to helping people with learning disabilities to live "as normal a life" as possible, without unnecessary segregation from the community. It emphasised the importance of close collaboration between health, social services and other local agencies.

1.13 In 1971 the Government recognised that achieving change would require "sustained action over many years", and the White Paper set national targets (for England and Wales) for development of services which would take 15 to 20 years to achieve. These included reducing the number of long-stay hospital places for adults from 52,000 to 27,000 and increasing the number of residential care places in the community from 4,000 to nearly 30,000. Day places in the community needed to increase by nearly 50,000. Long-stay hospital places for children were to reduce from 7,400 to 6,400.

1.14 Many of the aims of the 1971 White Paper have been achieved. Very few large institutions remain and there are no children in long-stay hospitals. Services in the community have expanded and developed, and more people with learning disabilities are in work. There are active self-advocacy and citizen advocacy movements and the voices of people with learning disabilities are heard more clearly.

1971 White Paper	Services in 2000
In 1969, there were 58,850 patients (adults and children) in NHS hospitals or units	Nearly 10,000 places in NHS facilities: 1,570 NHS long-stay places 1,550 NHS specialist places 1,520 NHS campus places 5,100 places in residential accommodation managed by the NHS
4,900 places in residential care homes	53,400 places in residential care
24,500 places in Adult Training Centres	Estimated 84,000 adults receiving community based services (day care, home help, meals etc), of whom 49,600 are in receipt of social services day services 6,630 patients using NHS day care facilities

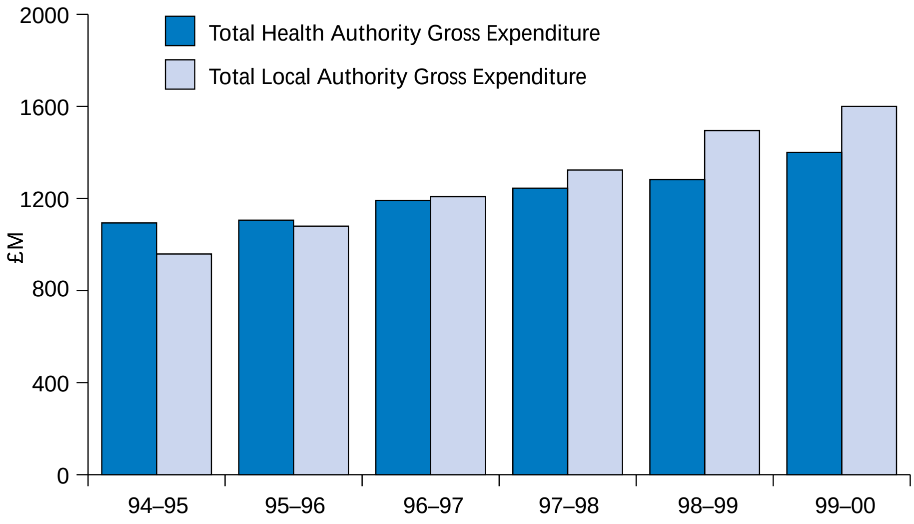
1.14 But more needs to be done. Too many people with learning disabilities and their families still lead lives apart, with limited opportunities and poor life chances. To maintain the momentum of change we now need to open up mainstream services, not create further separate specialist services. People with learning disabilities should have the same opportunities as other people to lead full and active lives and should receive the support needed to make this possible. The Government's agenda for reforming health and social care, modernising local government, promoting inclusive education and lifelong learning and Welfare to Work all offer major opportunities for improving the lives of people with learning disabilities. This can be done without losing the specialist expertise that currently exists.

Services and Expenditure

1.15 Many people with learning disabilities need additional support and services throughout their lives. This means that they have a longer and more intense involvement with public services than the vast majority of citizens. Services must provide them with safe, good quality care that delivers value for money.

1.16 Large amounts of public money are spent on learning disability services. Provisional health and social services expenditure on adults alone in 1999/2000 was over £3 billion: £1.4 billion on health and £l.6 billion on social services. In addition, about £308 million was spent by social services and £177 million by health on supporting disabled children, though not all of them have learning disabilities.

Figure 2 – Health and Local Authority Expenditure on Learning Disability



The figures for 1999/2000 are provisional.

1.17 The expansion of and improvement in some services has undoubtedly led to better outcomes for many people with learning disabilities. However, this does not mean services fully meet their needs. Research has consistently shown: variable quality of community based services; concerns about shortfalls of provision in particular services; and varying degrees of commitment to learning disability services by local authorities and health authorities.

Problems Facing Learning Disability Services

Social Exclusion

1.18 Despite the efforts of some highly committed staff, public services have failed to make consistent progress in overcoming the social exclusion of people with learning disabilities. These are some of the issues to be addressed:

Families with disabled children have higher costs as a result of the child's disability coupled with diminished employment prospects. Their housing needs may not be adequately met. There is little evidence of a flexible and co-ordinated approach to support by health, education and social services, and there is significant unmet need for short breaks.

Young disabled people at the point of transition to adult life often leave school without a clear route towards a fulfilling and productive adult life.

Carers can feel undervalued by public services, lacking the right information and enough support to meet their lifelong caring responsibilities.

Choice and Control. Many people with learning disabilities have little choice or control in their lives. Recent research shows only 6% of people with learning disabilities having control over who they lived with and 1% over choice of carer. Advocacy services are patchy and inconsistent. Direct payments have been slow to take off for people with learning disabilities.

Health Care. The substantial health care needs of people with learning disabilities too often go unmet. They can experience avoidable illness and die prematurely.

Housing can be the key to achieving social inclusion, but the number supported to live independently in the community, for example, remains small. Many have no real choice and receive little advice about possible housing options.

Day services frequently fail to provide sufficiently flexible and individual support. Some large day centres offer little more than warehousing and do not help people with learning disabilities undertake a wider range of individually tailored activities.

Social Isolation remains a problem for too many people with learning disabilities. A recent study[5] found that only 30% had a friend who was not either learning disabled, or part of their family or paid to care for them.

Employment is a major aspiration for people with learning disabilities, but less than 10% nationally are in work, so most people remain heavily dependent on social security benefits.

The needs of people with learning disabilities from minority ethnic communities are too often overlooked. Key findings from the study by the Centre for Research in Primary Care at the University of Leeds published alongside *Valuing People* included:

- prevalence of learning disability in some South Asian communities can be up to three times greater than in the general population;
- diagnosis is often made at a later age than for the population as a whole and parents receive less information about their child's condition and the support available;
- social exclusion is made more severe by language barriers and racism, and negative stereotypes and attitudes contribute to disadvantage;
- carers who do not speak English receive less information about their support role and experience high levels of stress; and
- agencies often underestimate people's attachments to cultural traditions and religious beliefs.

Inconsistency in Service Provision

1.19 The national statistics on learning disability conceal great variation across the country in terms of availability and coverage of services, as well as quality. Findings from three recent Department of Health studies of local authorities and their comparable health authorities – *Facing The Facts,*[6] *The London Learning Disability Strategic Framework* and a survey of 24 local authorities carried out during the development of the new strategy – show we are far from achieving consistency and equity for people with learning disabilities and their families.

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[5] The Quality and Costs of Residential Supports for People with Learning Disabilities, Summary & Implications (Hester Adrian Research Centre, University of Manchester, 1999).

[6] Facing the Facts: Services for People with Learning Disabilities – A Policy Impact Study of Social Care and Health Services (Department of Health 1999).

1.20 The main variations in social services and the NHS include:

- **Expenditure:** In London, social services expenditure per 10,000 population ranges from under £200,000 to £500,000. Health spend per 10,000 population ranges from under £100,000 to £450,000;
- **Day Services:** attendance at day centres ranges from 3 to 198 per 10,000 population, with higher figures generally associated with traditional day centres. Cost per attendance ranged from £18 to £112. We also know that some 20,000 people with learning disabilities – often the most severely disabled or those with challenging behaviour – do not attend a day service;
- **Short Breaks:** *Facing the Facts* found that the number of bed nights paid for by local authorities per 10,000 population ranged from 25 in a unitary authority to 492 in a shire county. For the special survey the range was 1 to 406 per 10,000 population. The last national Social Services Inspectorate inspection[7] found that short breaks were generally in short supply; and
- **Accommodation:** across the country the number of adults receiving care in publicly funded accommodation ranges from 12.74 per 10,000 population aged 18–64 to 59.20. Few places offer real choice.

1.21 The Government is committed to tackling the postcode lottery revealed here. It will be one of the key challenges in implementing the new strategy.

Management of Services

1.22 Good management of learning disability services requires:

- **strong partnership working:** while learning disability has been at the forefront of making use of the flexibilities under the Health Act 1999, many areas have yet to achieve real partnership between health and social care. Joint commissioning has been slow to take off. Few areas have partnerships involving service users, their families and the wider range of agencies.
- **good planning to ensure that services are responsive:** Few places attempt to have the individual's aspirations, needs and views as the driving force for providing services.

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[7] Moving into the Mainstream: The Report of a National Inspection of Services for Adults with Learning Disabilities (Department of Health 1998)

- **a highly skilled workforce:** we know that levels of training and qualification in the learning disability workforce remain low and there are shortages of key professionals and care staff.

The Way Forward

1.23 There is no "quick fix" solution to these problems; tackling them requires radical change from all of us. We need to develop a new approach to delivering better life chances for people with learning disabilities. We can no longer tolerate services which leave people isolated and marginalised. Good quality public services should offer new opportunities for people with learning disabilities to lead full and productive lives as valued members of their local communities. Our proposals are intended to:

- tackle social exclusion and achieve better life chances;
- ensure value for money from the large public investment in learning disability services;
- reduce variation and promote consistency and equity of services across the country;
- promote effective partnership working at all levels to ensure a really person-centred approach to delivering quality services;
- drive up standards by encouraging an evidence-based approach to service provision and practice.

CHAPTER 2

THE NEW VISION

2.1 Improving the lives of people with learning disabilities requires commitment nationally and locally to strong principles, a firm value base and clear objectives for services. Each individual should have the support and opportunity to be the person he or she wants to be.

Key Principles: Rights, Independence, Choice, and Inclusion

2.2 There are four key principles at the heart of the Government's proposals in *Valuing People*:

Legal and Civil Rights: The Government is committed to enforceable civil rights for disabled people in order to eradicate discrimination in society. People with learning disabilities have the right to a decent education, to grow up to vote, to marry and have a family, and to express their opinions, with help and support to do so where necessary. The Government is committed to providing comprehensive guidance for electoral administrators on helping disabled people, including those with learning disabilities, through the whole electoral process – from registering to vote until polling day itself.

"People with learning disabilities are citizens too"

All public services will treat people with learning disabilities as individuals with respect for their dignity, and challenge discrimination on all grounds including disability. People with learning disabilities will also receive the full protection of the law when necessary.

Independence: Promoting independence is a key aim for the Government's modernisation agenda. Nowhere is it of greater importance than for people with learning disabilities. While people's individual needs will differ, the starting presumption should be one of independence, rather than dependence, with public services providing the support needed to maximise this. Independence in this context does not mean doing everything unaided.

"All this can be done … by believing that people with learning disabilities can move on and be independent"

Choice: Like other people, people with learning disabilities want a real say in where they live, what work they should do and who looks after them. But for too many people with learning disabilities, these are currently unattainable goals. We believe that everyone should be able to make choices. This includes people with severe and profound disabilities who, with the right help and support, can make important choices and express preferences about their day to day lives.

Inclusion: Being part of the mainstream is something most of us take for granted. We go to work, look after our families, visit our GP, use transport, go to the swimming pool or cinema. Inclusion means enabling people with learning disabilities to do those ordinary things, make use of mainstream services and be fully included in the local community.

> ***"People with learning disabilities have been saying for a long time that we can speak up for ourselves"***

> ***"People with learning disabilities can live just as good a life"***

Our Values

2.3 Our new proposals reflect these four key principles and we set out below how they can be realised at both national and local level. They are grounded in the legislation that confers rights on all citizens including people with learning disabilities:

- the Human Rights Act 1998;
- the Disability Discrimination Act 1995;
- the Race Relations Act 1976;
- the Race Relations (Amendment) Act 2000;
- the Sex Discrimination Act 1975; and
- the UN Convention on the Rights of the Child, which was adopted in the UK in January 1992.

2.4 The Disability Rights Commission established in April 2000 has a vital role to play in enabling all disabled people, including those with learning disabilities, to gain full access to their legal rights. It will ensure that the needs and views of people with learning disabilities are integral to all the Commission's work.

2.5 People who are vulnerable to exploitation have to be protected in law. The position of those who are vulnerable to sexual abuse and exploitation is considered in the report of the Sex Offences Review *Setting the Boundaries*. This includes discussion on the capacity to consent for very vulnerable people. That report recommends a new offence of a breach of a relationship of care which would cover sexual relationships between, for example, doctors and their patients, or between designated care providers and people receiving certain care services in the community.

Government Objectives for Learning Disability Services

2.6 If public services are to continue to improve we need both to set a clear direction and create clear objectives. The new Government objectives developed from our consultation process set out below provide this direction for all agencies working with people with learning disabilities. They are an essential first step in tackling unacceptable variation and promoting greater consistency and equity in services.

2.7 Our objectives reflect the partnership approach which is central to Valuing People and clarify the Government's expectations of all local agencies providing help to people with learning disabilities and their carers: social services, health, education, employment, housing, the Benefits Agency, transport and leisure services. Local voluntary groups and independent service providers also need to be part of the partnership. This approach is in line with the Government's principles for partnership working enshrined in the Local Strategic Partnerships now being introduced to co-ordinate implementation of local community strategies and the Government's strategy for neighbourhood renewal. Our partnership proposals set out in Chapter 9 will fit within the umbrella provided by Local Strategic Partnerships.

2.8 There are two categories of Government objectives for people with learning disabilities: the first deal with outcomes for people and the second concern systems needed in order to deliver better outcomes. We support the objectives with more detailed sub-objectives, which will be monitored through new performance indicators. Annex A contains the complete list.

2.9 These objectives will provide the focus for local action to implement our proposals. We will require local agencies to build on the Joint Investment Plans which are already expected to be in place for April 2001 in order to develop local action plans. Chapter 10 looks in further detail at the role and contents of these plans, along with arrangements for monitoring the implementation of the White Paper as a whole.

Objective 1: Maximising Opportunities for Disabled Children
To ensure that disabled children gain maximum life chance benefits from educational opportunities, health care and social care, while living with their families or in other appropriate settings in the community where their assessed needs are adequately met and reviewed.

Objective 2: Transition into Adult Life
As young people with learning disabilities move into adulthood, to ensure continuity of care and support for the young person and their family and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training or employment.

Objective 3: Enabling People To Have More Control Over Their Own Lives
To enable people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person-centred approach to planning the services they need

Objective 4: Supporting Carers
To increase the help and support carers receive from all local agencies in order to fulfil their family and caring roles effectively.

Objective 5: Good Health
To enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary.

Objective 6: Housing
To enable people with learning disabilities and their families to have greater choice and control over where, and how they live.

Objective 7: Fulfilling Lives
To enable people with learning disabilities to lead full and purposeful lives in their communities and to develop a range of friendships, activities and relationships.

Objective 8: Moving into Employment
To enable more people with learning disabilities to participate in all forms of employment, wherever possible in paid work and to make a valued contribution to the world of work.

Objective 9: Quality
To ensure that all agencies commission and provide high quality, evidence based and continuously improving services which promote both good outcomes and best value.

Objective 10. Workforce Training and Planning
To ensure that social and health care staff working with people with learning disabilities are appropriately skilled, trained and qualified, and to promote a better understanding of the needs of people with learning disabilities amongst the wider workforce.

Objective 11: Partnership Working
To promote holistic services for people with learning disabilities through effective partnership working between all relevant local agencies in the commissioning and delivery of services.

Action for Change

2.9 *Valuing People* sets out a major programme to improve life chances for people with learning disabilities. The Government will:

- Set out a new vision for services for disabled children and their families, to be delivered through an integrated approach by health, education and social care. Disabled children will be fully included as an integral part of the Government's major reform agenda for all children and families. The Quality Protects programme targets £60 million over the next three years on improving support for disabled children and their families;
- Enable disabled young people to have equal opportunities for moving into adult life, with new support from the Connexions Service;
- Give people with learning disabilities more choice and control by developing advocacy, extending direct payments and introducing a national framework for promoting a person-centred approach to planning. The Government is investing £1.3 million per annum for the next three years in establishing a National Citizen Advocacy Network and promoting self-advocacy, both in partnership with the voluntary sector;
- Provide £750,000 over the next three years to establish a National Learning Disability Information Centre and Helpline in partnership with Mencap;
- Enable all people with learning disabilities to have access to a health facilitator and to have a Health Action Plan;
- Complete the reprovision of the remaining long-stay hospitals to enable everyone still living there to move to more appropriate accommodation by April 2004;
- Take forward a five year programme for modernising day services to provide more individualised support, with clear targets and bridging finance;
- Set a new Government target for increasing employment for people with learning disabilities, backed by the development of local employment strategies;
- Introduce the new Learning Disability Awards Framework in April 2001 to provide a new route to qualification for care workers in the learning disability field; and

- Strengthen partnership working by giving local councils lead responsibility for establishing new Learning Disability Partnership Boards. These will build on existing partnership structures to bring together public, voluntary and independent agencies and the wider community within the overall framework of Local Strategic Partnerships. Partnership Boards will be responsible for implementation of the White Paper and will need to submit updated Joint Investment Plans (JIPs) setting out plans for local action to the Department of Health by 31 January 2002.

2.10 Making these changes happen requires a long-term implementation programme over at least the next five years. The Government will provide a strong national lead and will:

- Introduce a new Learning Disability Development Fund of up to £50 million from April 2002: up to £30 million per annum revenue and £20 million capital. The revenue element of the Fund will be created from NHS old long-stay funding as it is released overtime. Resources from the Fund may only be used where they are deployed as part of pooled budgets under the Health Act flexibilities enabling them to be targeted on supporting our key proposals;
- Establish a Learning Disability Task Force, bringing together a wide range of expertise including people with learning disabilities and carers;
- Set up a national Implementation Support Team; and
- Introduce a new Implementation Support Fund of £2.3 million a year for the next 3 years.

2.11 Chapters 3 to 8 set out the problems and challenges facing people with learning disabilities, their families, their carers and agencies providing services, describe what is currently being done and list the key actions to be taken to help address the problems.

PART TWO:

BETTER LIFE CHANCES FOR PEOPLE WITH LEARNING DISABILITIES

CHAPTER 3

DISABLED CHILDREN AND YOUNG PEOPLE

Government Objective: To ensure that disabled children gain maximum life chance benefits from educational opportunities, health care and social care, while living with their families or in other appropriate settings in the community where their assessed needs are adequately met and reviewed.

3.1 This chapter sets out the Government's proposals for maximising opportunities for disabled children and supporting young people's transition into adult life. It focuses in particular on the needs of learning disabled children and their families, but does so within a framework which applies equally to all disabled children. Many disabled children have more than one impairment and a majority have a learning disability. There are an estimated 1.7 million pupils in schools with special educational needs, of whom some 250,000 have statements of special educational need. Most of those children with statements will also be defined as disabled. We will build on existing health, social services and education programmes to develop an integrated approach to supporting disabled children. Children and their families want services that are not only efficient and effective, but also joined up and responsive. We propose to set new Government objectives and sub-objectives to be applied from April 2002. (See Annex A).

Problems and Challenges

3.2 Society creates many problems and poses many challenges for disabled children and their families. Despite these, many families are very successful in providing a good start in life for their disabled children. There is a compelling body of evidence from research and inspection reports that disabled children and their families face many barriers to full participation in society:

- too little family support, help in the home and too few short breaks especially for more severely disabled children;
- too often living in poverty;

- lack of key workers leading to poorly co-ordinated inter-agency support;
- frequent delay in diagnosis and identification of the child's impairments;
- lack of good information about what help is available;
- limited expectation of children's educational achievements;
- some children live in residential placements, which can increase isolation from home and family and increase vulnerability to abuse;
- too few opportunities to participate in sport, culture and leisure activities;
- inequalities in access and quality of NHS services;
- minority ethnic families experience these barriers disproportionately;
- lack of opportunities for disabled young people moving into adulthood.

3.3 Three main messages have come out of consultation with disabled children:

- treat us more like our brothers and sisters,
- we want to do the things other children do, not always 'something special', and
- give us a chance to be independent, get a job and have a home.

3.4 Research findings show parents of disabled children would like:

- key workers to help co-ordinate services;
- early identification of impairments and early intervention;
- simple accessible information about available services;
- greater access to family support, short breaks and support.

What more needs to be done

KEY ACTIONS – DISABLED CHILDREN

- New priority in Quality Protects programme: £60m of children's services grant earmarked for more support for families of disabled children from 2001/2 to 2003/4, resulting in more home based help and more access to key workers.
- Major Government programme to improve educational outcomes for children with special needs, based on collaborative working across health, education and social services.
- £220 million from 2001 to 2004 to improve the accessibility of mainstream schools for disabled children.
- A new duty on all LEAs to provide parent partnership services for families of children with SEN, supported by £18m Standards Fund grant in 2001/02.
- Joint DH/DFEE work on position of children in residential placements.
- Additional family support through statutory and voluntary sectors including co-ordinated health and social care packages to an additional 6,000 severely disabled children by 2002.
- From April 2001 the introduction of direct payments to give parents and disabled 16- and 17-year-olds greater choice in how they receive services.
- New National Information Centre for families of disabled children to be launched in 2001 by Contact a Family. Government funding of £500,000 per annum.
- Action to enable more disabled children to use sport, culture and leisure activities.
- £4m ringfenced in National Childcare Strategy for children with disabilities and SEN, enabling more staff to be employed to support disabled children.
- A multi-agency working party to develop practical guidance for professionals involved in identifying the special needs of children in the 0–2 age bracket.
- Early support and intervention to tackle the social exclusion of disabled children through cross Government programmes (Sure Start, The Children's Fund and Connexions).

- Improved social security benefits for families with disabled children, helping reduce child poverty.
- A new National Service Framework for children to reduce health inequalities and ensure that all children have fair access to and high standards of health care.
- Development of integrated services for children and young people with severe disabilities and complex needs a priority for use of the capital element of the Learning Disability Development Fund.
- New transition arrangements, through the Connexions Service, to improve opportunities for disabled young people to take part in education, training or employment.

Quality Protects Programme

3.5 The Quality Protects programme set up to improve children's social services will:

- increase provision of a wider range of flexible support services for families of disabled children including short breaks;
- help integrate disabled children into mainstream leisure and out of school services;
- provide more and better information for families and increase the availability of key workers and other measures to improve co-ordination.

3.6 From April 2001 disabled children will be included in the priority areas for the grant. £60m has been earmarked for services for disabled children and their families – £15 million in 2001/2002 and 2002/2003 and £30 million in 2003/2004.

Family Support

3.7 The Government has set a target for an additional 6,000 severely disabled children by 2002 to receive support by a co-ordinated care package from health and social services.

3.8 The Government is increasing funding to the Family Fund Trust which provides grants to help reduce the stress on families with severely disabled children, including grants to pay for holidays, washing machines and other services. In 2000/2001, the Government contributed funding of £25.4 million. This funding will be increased by £1m in 2001/02, £2m in 2002/03 and £3m in 2003/4.

The Cheviots Centre

The Cheviots Centre in Enfield provides a range of services to children who have severe learning disabilities, very challenging behaviour problems and life limiting conditions. They provide a range of core services to give families the support they need to be able to look after their disabled child at home. The Centre provides a service which is seamless, fast and responsive and includes:
holiday play schemes;
home care support;
a counselling service and a range of activity groups which runs 7 days a week.

3.9 The Government will continue to support the Diana Children's Community Nursing Teams. These teams work in partnership with other local agencies and provide physical, social and emotional support to children with life limiting disorders in their own homes as an alternative to hospital-based care.

3.10 From April 2001 through the SEN Programme of Action, the Government will provide local education authorities with £18m to support the development of parent partnership services, and will invest a further £2m to pilot arrangements for independent parental supporters in the expectation that these will be available in all areas from 2002/03.

3.11 The implementation of the Carers and Disabled Children Act 2000 will allow direct payments to be made from April 2001 to parents of disabled children, giving greater choice and flexibility in how they receive services.

3.12 Families need to be able to make informed choices about the services and support they need for their children and for themselves. From 2001, the Government is funding the charity Contact a Family by £500,000 per annum for three years, to set up a new National Information Centre for families with disabled children. This will include a national telephone help and advice line for disabled children and parents.

The Markfield Project

'To make the **best** playscheme ever we all promise:

To be nice and kind. To be treated with respect. To not swear or spit. Not to shout. To call people by their names and not 'oi'. Not to play with peoples wheelchairs. To have FREEDOM to play. A lot of excitement and fun. To be included. TO play FUN games. To not kick, hit or bully each other. To play with everyone and make new friends. To listen and be listened to. To have a GOOD time! TO be helped when needed. To go on trips, have adventures and learn new things.'

Promised by the children and staff on the summer playscheme 2000

Play, Leisure, Culture and Sport

3.13 Disabled children want support to do the things their peers do, such as going swimming or to a youth club. Participation in play and sporting activities can help build self-esteem and social skills. The Government is taking action by: increasing through the Quality Protects programme the numbers of disabled children involved in leisure and play activities; supporting 13% of New Opportunities Fund places going to children with special needs; ensuring that all children in Sure Start areas will have access to good quality play opportunities, including one to one support and adapted toys and equipment.

Education Services

SEN PROGRAMME OF ACTION

3.14 Education, as a key service for children, must be characterised by its inclusiveness and its high expectations for all children, including those children with special educational needs, and those who are disabled. The Government's aim is to encourage disabled children to reach their full potential. The SEN Programme of Action is committed to:

i) improving early identification and early intervention;

ii) supporting parents and carers;

iii) improving the SEN framework;

iv) developing a more inclusive education system;

v) developing knowledge and skills;

vi) working in partnership.

3.15 Through the programme the Government has pledged additional resources to improve the education of children with disabilities. From April 2001 £220m has been allocated, over three years, through the Schools Access Initiative, to improve the accessibility of mainstream schools. Further, for 2001–02, £82m in the Standards Fund is earmarked to improve provision for children with special educational needs.

3.16 The Government's Special Educational Needs and Disability Bill will:

- strengthen the right of children with SEN to be educated in mainstream schools;
- require LEAs to provide parents of children with SEN with advice and information, and a means of settling disputes with schools and LEAs;
- require schools to inform parents where they are making special educational provision for their child and allow schools to request a statutory assessment of a pupil's SEN;
- place duties to increase physical accessibility to school premises and to not treat disabled children less favourably compared to non disabled children;
- place new duties on schools and LEAs to make reasonable adjustments so disabled pupils are not placed at a substantial disadvantage to their non-disabled peers.

3.17 From 2002, the Government will use revised statistical arrangements to monitor the progress and attainment of children, including those with learning disabilities. All schools will set targets for the achievement of children working below age related expectations on the National Curriculum. Further, the Qualifications & Curriculum Authority will issue guidance to schools on target setting and assessment for children working below these age related expectations. This will help ensure higher expectations of and higher attainment by all children with special needs. The revised SEN Code of

Practice, together with practical guidance, will help schools better identify needs early and provide for those needs.

3.18 During 2001/02 the Department for Education and Employment and the Department and Health will build on this substantial programme by:

- developing guidance on good practice in early identification of SEN;
- issuing – alongside the revised SEN Code of Practice – practical guidance on involving disabled children in decisions about their education;
- working with the Disability Rights Commission on the production of a Code to help schools make reasonable adjustments to include disabled children fully in the life and curriculum of their school;
- helping schools share effective practice on the delivery of inclusive education;
- developing measures of attainment and personal and social development for children with SEN;
- ensure that health services, social care and family support services are provided as far as possible, in school, or in other ways which support children's education and the well being of families.

HEALTH CARE IN SCHOOLS

3.19 Many children with special needs in mainstream schools require considerable support from health and social services. Children should not be disadvantaged in terms of access to health care as a result of parents' choice of school. It is particularly important that a child's health treatment/therapy should be provided with minimum disruption to their education and, wherever possible, necessary health care support should be delivered through schools and in a way which supports families. The NHS Plan sets out the Government's commitment to provide 6,500 more NHS therapists and related professional staff by 2004, with 4,450 more training places. In the summer the Department of Health will issue guidance on implementation. This will encourage wider use of the Health Act flexibilities in order to develop more integrated partnership working.

3.20 The Department for Education and Employment is sponsoring a network of eleven SEN Regional Partnerships across England. These bring together groups of local education authorities, local health and social services plus the private and voluntary sectors. We will promote full collaboration in these partnerships and also across the Department of Health's regional task forces to ensure joined-up child centred services for disabled children.

3.21 *Saving Lives: Our Healthier Nation* set out a child-centred public health role for school nurses, working with individual children and young people, families, schools and communities to improve health and tackle inequality. Schools can have a tailored health plan agreed in partnership with the school nurse to address the health needs and education priorities of the school. School nurses will assess an individual child's health needs and initiate and develop programmes for children with medical or special education needs to maximise their learning potential, and to promote health and inclusion in school life.

Residential Placements

3.22 Some disabled children are placed in residential schools; others live in residential homes. Whilst many of these placements are highly valued by children and families, they may result in their isolation from normal childhood support. We do not know enough about these children. In 2001/02 the children in need census will help enable councils to identify how many disabled children are in residential homes. In 2001/02 the Department of Health and Department for Education and Employment will work together to find out more about the numbers, characteristics and outcomes relating to these children. We will develop arrangements which will create better linkages between children living in residential placements and their family, and ensure they are properly supported and protected by key agencies.

3.23 Disabled children living in residential placements are known to be particularly vulnerable to abuse. The Care Standards Act 2000 strengthens the safeguards for children living away from home. From April 2002, the new National Care Standards Commission will register children's homes (including those homes for disabled children currently registered as care homes) and inspect the welfare of children in all boarding schools and Further Education colleges with boarding provision. Separate standards will be introduced for residential special schools.

Early Years Developments

3.24 Early Years and Childcare Development Partnerships have a responsibility to ensure that all sectors of the community have equal access to childcare, regardless of their special educational needs or disability. From April 2001, £144.75 million will be available to support Partnerships' Plans. Included in this sum, is a ring-fenced amount of £ 4 million to provide childcare services for children with special educational needs or disabilities and other special groups. In addition Partnerships can, at their discretion, supplement this amount using their general childcare grant.

3.25 Current childcare tax credit rules do not support parents who use formal childcare in their own home. This poses a specific barrier to work for families with particular needs, such as those with disabled children who need home-based care. The Government announced in the 2001 Budget that it is to consider how these families might be helped, for example by extending the childcare tax credit to cover formal childcare in the home where it meets standards similar to those that will govern the regulation and accreditation of childminders.

3.26 The Early Excellence Centres programme is a test-bed for developing high quality integrated services for the early years. Participating centres offer integrated early education and childcare, family support and dissemination of good practice. There are now 35 centres with a key role in: supporting children and families with special educational needs; improving early identification of needs; promoting inclusion; enabling parents to cope. Evaluation of the pilot Early Excellence Centres found that they had increased the rates of inclusion in mainstream education for children identified as having SENs in early childhood and were cost effective.

3.27 The Government intends to establish a multi-agency working party, with representation from specialist organisations with an interest, to develop practical guidance for the range of professionals involved in identifying the special needs of children aged 0–2 and offering support to the children and their families. The guidance will provide examples of good practice and set out practical advice to help agencies enhance joint working.

Cross Government Programmes for Children and Young People

3.28 Disabled children will also benefit from three cross government programmes to help prevent vulnerable children and young people from becoming socially excluded:

- Sure Start partnerships help in identifying young children (0–4 year olds) with disabilities and ensuring the provision of early intervention and support. Targeted efforts are then made to ensure that identified children receive relevant support to help them enter successfully into early years education. The support by Sure Start includes support for families with special needs;
- The £450 million Children's Fund will help families of disabled children (primarily in the 5 to 13 age group) by support through multidisciplinary teams and local voluntary groups. Services might include support for parents of disabled children and mentoring schemes;
- The Connexions service will be available to help all young people (primarily 13–19-year-olds) make a successful transition from school to the world of work, training and further education. The Connexions Personal Advisers will have a key role in supporting disabled young people into adulthood.

Child Poverty

3.29 From April 2001, families with disabled children will benefit from the following:

- An increase in the disabled child premium in income related benefits by £7.40 per week on top of normal uprating. 80,000 families with disabled children will see a rise in this premium from £22.25 to £30 a week. This change will be mirrored by an increase from April 2001 of £7.40 a week over and above inflation of the disabled child tax credit in Working Families' Tax Credit and Disabled Person's Tax Credit;
- The Disabled Income Guarantee will be paid to families on low incomes with severely disabled children receiving the highest care component of Disability Living Allowance. Extra £11.05 a week for each eligible child;
- Severely disabled 3- and 4-year-olds will benefit from entitlement to the higher rate mobility component of Disability Living Allowance.

Health Services

ACCESS TO HEALTH CARE

3.30 Disabled children have exactly the same health care needs as other children in addition to any arising from their particular disabilities. The NHS provides a universal service for all based on clinical need and the Government is determined to ensure disabled children have the same access to services as other children. Discrimination on any grounds, including disability, has no place in the NHS. The Government has announced the development of a National Service Framework (NSF) for children. This will help us improve services for all children and families and ensure we reduce unacceptable variations in the standards of care and in access to care. As promised in the NHS Plan, the Government has also set targets for reducing inequalities in childhood mortality and is developing targets for reducing morbidity inequalities. From 2001 fair access to health care will be measured and managed through the NHS Performance Management Framework. We will also look further at how Patient Advocacy Liaison Groups (PALS) will help disabled children and their families.

Rosehill and Littlemore Sure Start is developing work on early identification of special needs in children via a special needs support worker (a commissioned service from the LEA) who uses a particular form of intervention therapy. The Asian Families Liaison Worker (a commissioned service from Oxford City Council) found that identifying learning difficulties is a significant issue among children from Asian families. She is working with the special needs support worker via home visits, nursery and playgroup settings to offer individual and group support to adults and children in liaison with the locality health team.

DIAGNOSIS IN EARLY CHILDHOOD

3.31 The NHS programme of surveillance and screening of children enables children with disabilities to be identified at an early stage. We provide funding for the development of training packages and information aimed at all health professionals to improve their knowledge of disability and to enhance their skills in sharing this information sensitively with the child, their parents and other family members. Liaison nurses are increasingly being used to help families through the trauma of major medical surgical interventions and to provide ongoing support.

COMPLEX HEALTH NEEDS

3.32 The Government is concerned to support the increasing numbers of children with complex medical needs, some of whom are dependent on technology. We will take steps to establish the numbers and socio-economic characteristics of these children. Support for these families will be given through the Quality Protects programme and through the New Opportunity Fund providing grants for projects offering palliative care to children with life limiting illness and their families.

3.33 In order to make further progress in improving services for children with complex needs and their families, we have made developing integrated health and social services facilities for such children and young people a priority area for the use of the capital element of the Learning Disability Development Fund.

CHILD AND ADOLESCENT MENTAL HEALTH SERVICES (CAMHS)

3.34 Children with physical or learning disabilities are more vulnerable to the full range of mental health disorders and the additional social, family and emotional stresses of everyday life. £50 million has already been allocated to improve child and adolescent mental health services over the period 1999 to 2001. The Government is committed to improving services for children and young people with mental health problems through the implementation of the NHS Plan. By May 2001, all health authorities and local councils must have an agreed joint CAMHS Development Strategy which sets out how local and national priorities are to be met, including 24-hour cover and outreach services and increasing early intervention and prevention programmes for children. Arrangements to provide CAMHS for learning disabled children will be included in all relevant planning arrangements for children.

TRANSITION INTO ADULT LIFE

Government Objective: As young people with learning disabilities move into adulthood, to ensure continuity of care and support for the young person and their family; and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training or employment.

Problems and Challenges

3.35 Disabled young people and their families often find the transition to adulthood both stressful and difficult. For many, there has been a lack of co-ordination between the relevant agencies and little involvement from the young person. Some young people are not transferred from children's to adult services with adequate health care plans, which results in their exclusion from adult services. This is likely to affect young people with severe learning disabilities and complex health needs in particular. Starting adult life should be a time of opportunity for young people. The Government wants to see more young people taking part in education and training, which will help them lead productive adult lives and find employment.

What more needs to be done

Making the Connexions Service work for Young People with Learning Disabilities

3.36 From April 2001, the new Connexions Service will be rolled out to provide all 13–19-year-olds with access to advice, guidance and support, through the creation of a network of personal advisers. These advisers will identify young people with learning disabilities; they must be invited to and attend annual reviews of all year 9 pupils with statements of SEN; and will work with the school and other relevant agencies to draw up the transition plans. Each Connexions Partnership must have sufficient Personal Advisers with the appropriate skills, experience and training to work with disabled young people. For young people leaving care the Children (Leaving Care) Act places a duty on councils to provide qualifying young people aged 16 and over in and leaving care with a personal adviser. There is such a significant overlap between the roles envisaged for the Act's advisers and Connexions advisers that the advisers provided by councils will also be well placed , with training, to act as Connexions advisers.

3.37 Connexions Partnerships will have responsibility for arranging with the local Learning and Skills Council and the Employment Service a review for the young person with learning disabilities in their 19th year, to agree arrangements for appropriate transition from the support provided by the Connexions Service, whilst ensuring continuity. Adult social services may need to be involved in some cases. Where young people are not ready to use the adult guidance services, Connexions Partnerships will continue to support them, with the aim of helping them make use of the adult systems and to reduce dependency on the Connexions Service. These arrangements can extend up to their 25th birthday.

Connecting with Connexions – a Community Care Development Centre Project

Connexions pilot Personal Advisers (PAs) in Lewisham are exploring how to prepare young people with learning disabilities for the world of work. Two PAs appointed by London South Bank Careers to special schools are linking with two experienced supported employment agencies (Sabre and STATUS). The PAs are learning about supported employment and meeting job coaches and people with learning disabilities who have jobs. The outcome will be information about guidance and materials to help link Connexions with work options and how to support PAs to work with young people with learning disabilities.

Young People and Person-centred Planning

3.38 Chapter 4 sets out the Government's proposals for a person-centred approach to planning services for adults with learning disabilities. Local councils will take the lead in ensuring that local Learning Disability Partnership Boards responsible for planning and commissioning services for adults agree a framework for the development of person-centred planning. This will build on the assessment and planning for young people already undertaken by Connexions. The Government will issue further guidance on person-centred planning for adults with learning disabilities in 2001. Local agencies will be expected to have introduced person-centred planning for all young people moving from children's to adult's services by 2003.

3.39 There will also need to be effective links in place between children's and adults services in both health and social care. We will expect Learning Disability Partnership Boards to identify a member with lead responsibility for transition issues. Ensuring continuity in health care will be a key element of the new Health Action Plan for people with learning disabilities discussed in Chapter 6. For social care, the Director of Social Services will be required to ensure that good links are in place between children's and adult services for people with learning disabilities as part of his/her new responsibility for quality under the Social Care Quality Framework.

CHAPTER 4

MORE CHOICE AND CONTROL FOR PEOPLE WITH LEARNING DISABILITIES

Government Objective: To enable people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person-centred approach to planning the services and support they need.

The proposals in this chapter will be central to delivering the Government's four key principles. The rights of people with learning disabilities need to be promoted. They also need help in order to achieve greater choice, independence and inclusion in all aspects of their lives. Services should respond to the wider aspirations of people with learning disabilities and give them more choice and control.

Problems and Challenges

4.1 People with learning disabilities currently have little control over their own lives, though almost all, including the most severely disabled, are capable of making choices and expressing their views and preferences. The current problems are:

- Services have been too slow to recognise that people with learning disabilities have rights like other citizens;
- Provision of advocacy services is patchy;
- People with learning disabilities have little involvement in decision making;
- Few people with learning disabilities receive direct payments;
- People with learning disabilities and their families are not central to the planning process;
- Not enough effort to communicate with people with learning disabilities in accessible ways.

4.2 The challenge for public services is to find ways to give people with learning disabilities more control over their lives through:

- Developing and expanding advocacy services, particularly citizen advocacy and self-advocacy;
- Fully involving them in decisions affecting their lives;
- Increasing the number who receive direct payments;
- Developing a person-centred approach to planning services;
- Improving information and communication with people with learning disabilities.

What More Needs To Be Done

KEY ACTIONS – CHOICE AND CONTROL FOR PEOPLE WITH LEARNING DISABILITIES

- Disability Rights Commission to work for people with learning disabilities.
- £1.3 million per annum for the next three years to develop and expand advocacy services in partnership with the voluntary sector.
- Legislation to extend eligibility for direct payments supported by implementation programme to promote take up.
- Department of Health guidance to be issued in 2001 on a person-centred approach to planning services.
- Transfer of responsibility to local councils for people with preserved rights: Councils required to offer direct payments.
- The Learning Disability Development Fund will provide resources to support development of person-centred planning.
- National Forum for people with learning disabilities set up in 2001.
- Advice on involving people with learning disabilities in decision making to be issued.
- People with learning disabilities to benefit from expansion and integration of community equipment services.

Disability Rights Commission

4.3 The Disability Rights Commission will play an important role in helping individuals enforce their rights under the Disability Discrimination Act. A group is being set up to advise the Commission on issues relating to people with learning disabilities. It has drawn up a programme to ensure that the voices of people with disabilities are heard by:

- Involving them in developing the Commission's strategic plan and consultations on major policy issues;
- Producing materials in accessible formats;
- Advising the public sector and business on best practice in involving and communicating with people with learning disabilities.

4.4 The Department of Health will also work with the Commission to consider the way forward for advocacy for all disabled people.

Advocacy

4.5 Effective advocacy can transform the lives of people with learning disabilities by enabling them to express their wishes and aspirations and make real choices. Advocacy helps people put forward their views and play an active part in planning and designing services which are responsive to their needs. This applies to people with severe and profound disabilities and to the less severely disabled.

4.6 With the right support, many people with learning disabilities can become effective self-advocates. The growth of the self-advocacy movement[9] shows how people with learning disabilities can make a real difference to service development and delivery. Citizen advocates[10] make a vital contribution to enabling the voices of people with more complex disabilities to be heard.

4.7 Both citizen advocacy and self-advocacy are unevenly developed across the country. Barriers to future development include: insecure funding; limited support for local groups; and potential for conflicts of interest with statutory agencies who provide funding. This must change.

Swindon People First

Established in 1988 since 1995 this self-advocacy group has had about 120 members involved in activities such as consultation with members about the services they use; sitting on advisory panels and being members of a large Joint Working Group; interviewing managers with social services for their jobs; lay assessing and consultation with members who don't use words to communicate. They currently run a Direct Payments Support Scheme as well as a research project into how direct payments are working for people with learning disabilities across the UK. They have been very successful in obtaining funding from trusts and charities for project development and are in a promising position to build for the future.

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[9] Self-advocacy is people speaking up for themselves

[10] Citizen advocates (ie volunteers) create a relationship with a person with learning disabilities', seeking to understand and represent the person with learning disabilities' views

4.8 The NHS Plan states that by 2002 an NHS-wide Patient and Advocacy Liaison Service (PALS) will be established in every NHS Trust, beginning with every major hospital. This will include all those Trusts offering specialist learning disability services and other health services to people with learning disabilities. PALS will be an accessible and visible service whose role will be to resolve patients', families', and carers' problems and concerns as quickly as possible. PALS will not replace external advocacy services for learning disabled people, but, where necessary, it will be able to provide signposting to independent advocacy services.

4.9 The Government's long-term aim is to have a range of independent advocacy services available in each area so that people with learning disabilities can choose the one which best meets their needs. To achieve this, we will work in partnership with citizen advocacy and self-advocacy groups to promote and sustain development of independent local advocacy schemes. We are investing at least £1.3 million for each of the next three years for this purpose. We will monitor and evaluate the impact of this funding. The new funding will be used to:

- establish a National Citizen Advocacy Network for Learning Disability led by a consortium of leading voluntary organisations. It will be charged with distributing funds to local groups in an equitable and open manner, operating within criteria drawn up after consultation with relevant interests and agreed by the Department of Health. The aim will be to work towards at least one citizen advocacy group in each local authority area. We will take steps to ensure this funding is not used to replace existing funding sources for citizen advocacy;
- increase funding for local self-advocacy groups and strengthen the national infrastructure for self-advocacy. The Department of Health will invite bids from self-advocacy groups in each of its eight regions. The Government will work in partnership with the self-advocacy movement to promote the development of a clear national voice for people with learning disabilities.

4.10 Development of, and support for, advocacy services will also be a priority area for the Learning Disability Development Fund.

4.11 People with learning disabilities from minority ethnic communities can find it particularly difficult to gain access to the advocacy support they need. The Government will ensure that our new initiatives are responsive to their needs. The Department of Health will issue good practice materials to help with this.

'The Government has got to understand how we feel about these things.' (Malcolm)

'The [advocate] explains to me what I don't understand, what social services are talking about. If I didn't understand what the questions were, she'd repeat it and explain it. She was brilliant. Helped me with debts. Had problems with money-still have problems. Calming me down when I get stressed. Any problems I tell her and she tried to help me. If I'm in bad distress I tell [her] and she tells me who to get in touch with. I've never had anyone better.' (Ruby)

Direct Payments

4.12 Direct payments give local councils power to offer people money to pay for the support they have been assessed as needing in lieu of providing the services direct. The Carers and Disabled Children Act 2000 extends direct payments to carers and to disabled 16- and 17-year-olds. The Health and Social Care Bill includes provisions to extend the scope of direct payments. Subject to Parliamentary approval the legislation will:

- require local councils to make direct payments where an individual who requests and consents to one meets the criteria;
- enable local councils to make direct payments to disabled parents to meet their child's needs and for local council provided rehabilitation services.

4.13 Direct payments are highly effective in enabling people with learning disabilities to gain greater control over their lives, because they can choose how they want their support needs met. In autumn 2000 only 216 people with learning disabilities were receiving such payments out of a total of over 3,700 people. This needs to change. The provisions in the Health and Social Care Bill are intended to result in more people with learning disabilities receiving direct payments.

4.14 The success of direct payments for people with learning disabilities depends on good support services. Most local councils operate support schemes, but often these are focused on the types of support people with physical disabilities may need. Schemes must be accessible to people with learning disabilities, so that they too have the right support to manage a direct payment and remain in control. Our proposals for developing and expanding advocacy services will enable more people to access direct payments. Subject to the Health and Social Care Bill completing its passage through Parliament, the Department of Health will issue guidance on the new provisions and how people with learning disabilities can be helped to use direct payments. This will include provision of support services.

4.15 Promoting direct payments is a key element of our new vision for people with learning disabilities. The national Implementation Support Team will focus on working with local councils to achieve higher take-up. The Department of Health will consult on a performance indicator in the Personal Social Services Performance Assessment Framework.

Hampshire Social Services operates a flexible system to make direct payments available to people with learning disabilities. This minimises potential blocks. People have the option to purchase care from agencies rather than employing personal assistants. Existing networks support the person receiving the direct payment or, where these do not exist, arrangements are made to provide the individual support required.

Two examples

One young man, living with his parents, receives a direct payment to employ a support worker from an agency for short breaks. Breaks can be a few hours in the evening and weekends or longer. He chooses how to spend his time with the support worker and his mother has a break.

One man living with his mother wanted to move on from the day service and have more control over what he did and when. He now purchases the services of a support worker from a local agency to help him go to local leisure facilities in the evening. The local self-advocacy group, which has set up a support system for people receiving direct payments provides the support.

People with Preserved Rights

4.16 People in residential care on 31 March 1993 have preserved rights to receive a higher rate of income support from which they can purchase their care. Around 30,000 are younger disabled people. Following the announcement in the NHS Plan, the Health and Social Care Bill contains provisions to transfer responsibility for their assessment and care management to local authorities. This will give this group more choice about where they live and close the shortfall in funding. The Department of Social Security will transfer resources to local authorities for their new responsibilities. Subject to Parliamentary approval these changes will come into effect in April 2002. Guidance on this change will say that councils will be required to offer the option of direct payments to anyone who meets the prescribed conditions.

A Person-Centred Approach to Planning

4.17 A person-centred approach to planning means that planning should start with the individual (not with services), and take account of their wishes and aspirations. Person-centred planning is a mechanism for reflecting the needs and preferences of a person with a learning disability and covers such issues as housing, education, employment and leisure.

4.18 Care management is the main way individuals link with services. The type and extent of care management can vary markedly between council areas. This can result in duplicated assessments and care plans for some people with learning disabilities, while others receive insufficient attention. Some people receiving publicly funded services have problems accessing the care management they need. This confusing and inconsistent situation is unacceptable.

PRIORITIES FOR PERSON-CENTRED PLANNING

4.19 The Government will issue further guidance later this year to help local councils develop a person-centred approach and put people with learning disabilities and their families at the centre of the process of planning services for and with them. We expect Learning Disability Partnership Boards to use this guidance to agree a local framework by April 2002. It will take time to develop a person-centred approach to planning for everyone who needs services. Local areas may wish to develop their own priorities, paying particular

Alan is in his 50s and now lives in his own terraced house. He wasn't happy living in a hostel nor in his own flat with support from a key worker. He met someone who was getting a direct payment and decided '*– yes that's for me! I like the idea of employing my own personal assistants who I could ask to do what I wanted when I wanted.*' His social worker put him in touch with the local independent direct payments support agency. They helped him apply for a direct payment, advertise for personal assistants and prepare job descriptions and contracts. They arranged training about direct payments and employment. Alan said '*Without the training I wouldn't have been able to cope with a direct payment.*' Now he gives talks to social workers and people with learning disabilities about how to get a direct payment.

attention to those individuals who are poorly served. However the Government also has some specific priorities. These include:

By 2003:

- People still living in long-stay hospitals;
- Young people moving from children's to adult services.

By 2004 we expect to see significant progress in the following areas:

- People using large day centres;
- People living in the family home with carers aged over 70;
- People living on NHS residential campuses.

Susan, who is in her early 20s, is severely disabled. She makes her views known through her actions, verbal responses, facial expressions and moods. Susan's circle of support realised she was unhappy with her existing services and put together a package of money to enable her to live independently. Direct payments are part of the package. The circle formed itself into a user-controlled trust fund, which manages the direct payment. Susan's expressions and views guide how the money is spent, so she is in control of the use of the money. Direct payments mean Susan can live in her own house with her own rota of support workers. She is relaxed, confident and content with a full social life and is very much part of the community.

CARE MANAGEMENT

4.20 Care management will continue to be the formal mechanism for linking individuals with public services. Its systems must be responsive to person-centred planning, and have the capacity to deliver the kinds of individualised services likely to emerge from the process. It must link effectively with other plans including:

- vocational plans (led by Connexions for young people);
- health action plans (led by an identified health professional);
- housing plans, (including a joint housing/community care assessment);
- communications plans, (where the person has communications difficulties).

4.21 Development of a person-centred approach requires real changes in organisational culture and practice. Achieving these changes should be a priority for Partnership Boards.

4.22 Given the importance of person-centred planning as a tool for achieving change, we will make supporting its implementation one of the priorities for the Learning Disability Development Fund and the Implementation Support Team. Its development and the responses of the services will be monitored, along with the extent to which person-centred services emerge as a consequence.

FAIR ACCESS TO CARE

4.23 Later in 2001 the Government will be issuing the Fair Access to Care (FACS) guidance. This will set out how eligibility for adult social care services should be determined, and following implementation from April 2002, should lead to a more consistent and fairer access to care services. The guidance will also cover procedures for reviewing adult service users' needs and continuing eligibility for support. At the same time, the Government will publish general principles of assessment to update previous 1990/1991 guidance.

4.24 In implementing this guidance councils will need to take a corporate approach, with eligibility criteria agreed across all council departments and with health and other local agencies. Councils and local health bodies will be specifically asked to develop joint eligibility criteria for adult social care and continuing health care. Partnership Boards will need to ensure that all systems are compatible with this guidance.

4.25 Person-centred frameworks will need to be fully compatible with the locally agreed joint eligibility criteria which councils and local health bodies will be asked to develop following the Fair Access to Care guidance.

INDIVIDUAL CO-ORDINATION

4.26 By July 2002 all people with learning disabilities who make substantial and long-term use of publicly funded services should have a named individual to act as their service co-ordinator. The co-ordinator will be responsible for ensuring effective organisation and monitoring of services by all relevant agencies and will be the first point of contact for people with learning disabilities and their families.

Involvement In Policy Development and Decision Making

4.27 People with learning disabilities should be fully involved in the decision making processes that affect their lives. This applies to decisions on day to day matters such as choice of activities, operational matters such as staff selection and strategic matters such as changes to eligibility criteria. It is no longer acceptable for organisations to view people with learning disabilities as passive recipients of services; they must instead be seen as active partners. Further advice will be issued in 2001 to help local agencies involve people with learning disabilities in decision making.

4.28 At national level, we have begun to involve people with learning disabilities in policy development. The Service Users Advisory Group played an important role in developing the new strategy. During 2001 the Group will develop into a more nationally representative forum linking with local groups of learning disabled people. The National Forum for People with Learning Disabilities will contribute to monitoring the impact of *Valuing People*.

4.29 *Making Decisions* (published October 1999) set out the Government's proposals to reform the law in order to improve and clarify the decision making process for those people unable to make decisions for themselves. The proposals include: definition of capacity; factors to be taken into account in assessing a person's best interest and the introduction of general authority to act reasonably which will regulate day-to-day decisions. *Making Decisions* also sets out proposals to introduce Continuing Powers of Attorney to replace Enduring Powers of Attorney, and a modernised court which will deal with all areas of decision making for adults without capacity.

"People First has learnt a lot by being part of this Strategy Group and we hope that we can work together more in the future. **I am proud of being included in this group**.

It means a lot to me to work together with such a good team of people who are all committed to supporting people with learning difficulties in their hard struggle to live independent lives. (Carol)

Communication and Equipment

4.30 The Government expects organisations working with learning disabled people to develop communication policies and produce and disseminate information in accessible formats. For those with severe disabilities this may require individual communication techniques and effective use of new technology.

4.31 People with learning disabilities may need specialist equipment because they also have a physical disability or sensory impairment. Assistive technology can increase their control, choice and independence through improving cognitive and social functioning. It can also enable people with learning disabilities to make good use of education, training and employment opportunities. From April 2001 councils with social services responsibilities and the NHS will receive additional funding to improve and expand community equipment services. By 2004 the Government expects health and social services to integrate their community equipment services, and increase by 50% the number of people benefiting from them.

CHAPTER 5

SUPPORTING CARERS

Government Objective: To increase the help and support carers receive from all local agencies in order to fulfil their family and caring roles effectively.

This Chapter focuses on the rights of carers. Carers need to be confident that public services will provide reliable support for their family members with learning disabilities, and that our proposals for improving services will bring them benefits. The support and commitment of carers is critical in enabling people with learning disabilities to achieve independence, choice and inclusion.

Problems and Challenges

5.1 Caring for a family member with a learning disability is a lifelong commitment, which continues even when the person is living away from the family home. Carers make a vital contribution to the lives of people with learning disabilities, often providing most of the support they need. They are a crucial resource for ensuring that people with learning disabilities can live in the community. We have no precise data on numbers, but it is estimated that some 60% of adults with learning disabilities live with their families. Statutory agencies do not always properly recognise the extent of carers' contribution or its value.

5.2 Carers face many problems and challenges. They need:

- More and better information;
- Better assessment of their own needs;
- Improved access to support services such as day services and short break services (respite care) particularly for those with more severe disabilities;
- To be treated as valued partners by local agencies, not as barriers to their son's or daughter's greater independence.

5.3 The challenge is to ensure that carers:

- receive the right support to help them in their caring role;
- obtain relevant information about services;
- know who to approach for advice and help;
- are respected and treated as individuals in their own right;
- make their voices heard at national and local level.

What More Needs To Be Done

KEY ACTIONS – CARERS

- Carers of people with learning disabilities to benefit from all mainstream carers initiatives.
- Implementation of Carers and Disabled Children Act 2000.
- In partnership with Mencap the Government will provide £250,000 per annum for the next three years to develop a National Learning Disability Information Centre and Help Line.
- New guidance on exclusions from services.
- Local councils to pay particular attention to identifying and supporting carers aged over 70 and carers from minority ethnic communities.
- Carers and carer organisations to be represented on Learning Disability Task Force.

National Carers Strategy

5.4 The Government is determined to improve support for carers. *Caring about Carers: the Report of the National Carers Strategy* sets out our general approach. Social security benefits are being increased to help carers. From April 2001 a package of extra support worth £500 million over the next three years will help some 300,000 carers. We are increasing the carer premium in income related benefits by 70% (from £14.15 to £24.40). We are also raising the earnings limit (now £50 per week) in the Invalid Care Allowance (ICA) to the level of Lower Earnings Limit (currently £67 per week). Subject to a suitable legislative opportunity we will extend the opportunity to claim ICA to people aged 65 and over and the entitlement to ICA for up to 8 weeks after the death of the disabled person will also help carers.

5.5 The Government expects carers of people with learning disabilities to benefit from all mainstream carer initiatives. This requires effective targeting at local and national levels. Carers must be able to obtain information, advice and help easily from local agencies, especially local councils with social services responsibilities and must be given a single point of contact.

Implementation of the Carers and Disabled Children Act 2000

5.6 The Carers and Disabled Children Act 2000 comes into force in April 2001. It extends a carer's right to an assessment, already provided for in the Carers and Recognition and Services Act 1995, to carers where the person cared for has refused an assessment or has refused community care services, and gives local councils the power to offer carers services to support them in their caring role and to help them maintain their own health and well being. The Department of Health is issuing guidance to local councils on implementing the legislation together with a leaflet *The Carers Guide to a Carer's Assessment* to be made available to all carers. The Government is committed to ensuring that these new rights become a reality. We shall consult on a new Performance Indicator to monitor how many people with learning disabilities are receiving breaks services (respite care).

Excluding People from Services

5.7 Excluding people with learning disabilities from services if they are found to be difficult to handle or present with challenging behaviour represents a major cause of stress for carers, who may be left unsupported to cope with their son or daughter at home. This practice is unacceptable and families must not be left to cope unaided. No service should be withdrawn on these grounds without identifying alternative options and putting a suitable alternative service in place where possible. Decisions to exclude a person with learning disabilities from a service should always be referred to the Learning Disability Partnership Board, which will be responsible for the provision of alternative services in such cases, provided the person meets the eligibility criteria. This issue will be addressed in the guidance to be issued on implementing *Valuing People*.

Tameside: Flexible Respite Services

Three years ago the council identified money within the learning disability budget to develop an alternative option to the building based respite service. A flexible service has now been developed to support people in their own homes or in accessing community services and provide a break for carers. People access it for between 1 or 2 hours and 10 hours a week, which has opened up many opportunities for people to go to community facilities with individual support. Last year the council used money from the Carers Grant and the Promoting Independence Grant to expand the service. It now provides 340–350 hours a month to around 36 people. The independent sector provides the service: about 90% is delivered by the same provider who runs the building based respite care service.

Information for Carers

5.8 Carers need more and better information provided in ways that are easily accessible. The most effective information exchange is often between carers, who share experiences and solutions. These networks also need reliable information from others. Many organisations provide telephone and written advice, but there is currently no national Information Centre or Help Line for people needing help on learning disability issues.

5.9 In order to fill this gap, the Department of Health is providing £750,000 over the next 3 years to enable Mencap to work with other key interests to establish a National Learning Disability Information Centre and telephone help and advice line. The Centre will provide help to all who need it, including people with learning disabilities and professionals, but we expect it to have a particularly important role for carers. Services to be provided will include:

- Advice on all aspects of learning disability and the services and help people with learning disabilities need;
- Links and collaboration with the Contact a Family Information Centre for Children (see paragraph 3.12);
- Links with other databases and websites, including the National Electronic Library for Health, the Social Care Institute of Excellence, and NHS Direct on line;
- Putting people in touch with local support groups.

The Carers Grant: Meeting the Needs of Older Carers and Carers from Minority Ethnic Communities

5.10 *Family Matters, Counting Families In* published alongside *Valuing People* identifies three groups of carers who face additional pressures: older carers (those aged 70 or over), carers from minority ethnic communities and carers whose sons or daughters are going through transition from school to adult life. Chapter 3 looks at transition, and we discuss below the other two priority groups. Both face additional difficulties in carrying out their caring role effectively.

5.11 It is estimated that a third of people with learning disabilities living in the family home are living with a carer aged 70 or over. Many are sole carers with reduced support. In many cases the learning disabled person also takes on a caring role, but this is not generally recognised and they are often not properly supported. There is some evidence to suggest that up to 25% of people with learning disabilities do not become known to statutory agencies until later in life, when the parent becomes too frail to continue caring for their adult son or daughter. Lack of planning for the future creates anxiety and stress for the parent and the learning disabled person. This group is one of the priority groups for developing a person-centred approach to planning (see paragraph 4.19). We propose to introduce a Performance Indicator: % of carers aged 70 or over for whom a plan has been agreed. This will be monitored as part of the arrangements for monitoring the White Paper.

5.12 Difficulties facing carers from minority ethnic communities include insensitivity to issues of culture and language and false assumptions about communities wishing to provide care within their own family environment or putting up barriers against statutory agencies. All services for carers should be responsive to the needs of people from minority ethnic communities.

5.13 The Carers Grant provides funds to help ensure that substantial and regular carers, who will include lifelong carers, get a break from caring when they need it. Analysis of the Grant's first year of operation (1999/2000) shows that at least 10% of the total grant of £20 million was spent on breaks for carers of adults with learning disabilities. Over the next 3 years the amount available for all carers will be £70 million/£85 million/£100 million.

5.14 The Department of Health will shortly issue new guidance for the Carers Grant 2001/02 which will encourage local councils to identify older carers and carers from minority ethnic communities.

5.15 The Department of Health will monitor the impact of its new guidelines as part of the process of monitoring the Grant. People living with carers aged 70 or over will also be an early priority for the introduction of person-centred planning.

Carers as Partners

5.16 It is essential that the voices of carers are clearly heard in policy development and implementation at both national and local levels. Carers should be treated as full partners by all agencies involved. The Government will ensure that carers are represented on the Learning Disability Task Force. We will also ensure that this group of carers contributes to the Department of Health's existing arrangements for discussing policy and practice issues with the generic national carers' organisations. We expect this to be mirrored at local level so that carers participate in debates about local policy development.

5.17 Carers have training needs and can also be a training resource. Local councils should offer them training opportunities so that they develop their skills. Professional staff can learn a great deal from their experience and expertise. The Government will require local agencies to ensure that carers and their organisations are fully involved in the development of local action plans for implementing the White Paper.

CHAPTER 6

IMPROVING HEALTH FOR PEOPLE WITH LEARNING DISABILITIES

Government Objective: To enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary.

This chapter shows how the Government's commitment in the NHS Plan to a person-centred health service which challenges discrimination on all grounds will improve health care for people with learning disabilities. Good health is an essential prerequisite for achieving independence, choice and inclusion.

Problems and challenges

6.1 Most people with learning disabilities have greater health needs than the rest of the population. They are more likely to experience mental illness and are more prone to chronic health problems, epilepsy, and physical and sensory disabilities. An increasing number of young people with severe and profound disabilities have complex health needs. Poor oral health may lead to chronic dental disease. As life expectancy increases age-related diseases such as stroke, heart disease, chronic respiratory disease and cancer are likely to be of particular concern. There is an above average death rate among younger people with learning disabilities.

6.2 Surveys have highlighted shortfalls in primary care and hospital provision. *Facing the Facts*, for example, found inconsistencies in the provision of health care in different parts of the country. When people with learning disabilities approached health care providers for assessment or treatment they often found difficulties in gaining access to the help they needed. The health needs of people with learning disabilities may not be recognised by doctors and care staff who have no experience of working with people who have difficulties in communication. Health outcomes for people with learning disabilities fall short when compared with outcomes for the non-disabled population. We know that:

- Few people with learning disabilities access health screening services with uptake rates for breast and cervical screening being especially poor.
- Research has highlighted inadequate diagnosis and treatment of specific medical conditions, including heart disease, hypothyroidism and osteoporosis.
- Studies of the management of people with challenging behaviour has shown an over-dependence on the use of psychotropic drugs with poor outcomes as a consequence.
- Doctors and care staff can fail to recognise the potential health complications of many of the conditions that cause learning disability.

6.3 Because mainstream health services have been slow in developing the capacity and skills to meet the needs of people with learning disabilities, some NHS specialist learning disability services have sought to provide all encompassing services on their own. As a result the wider NHS has failed to consider the needs of people with learning disabilities. This is the most important issue which the NHS needs to address for people with learning disabilities.

What More Needs To Be Done

KEY ACTIONS – HEALTH

- Action to reduce health inequalities: explore feasibility of establishing a confidential inquiry into mortality among people with learning disabilities.
- Action to challenge discrimination against people with learning disabilities from minority ethnic communities.
- Health facilitators identified for people with learning disabilities by Spring 2003.
- All people with a learning disability to be registered with a GP by June 2004.
- All people with a learning disability to have a Health Action Plan by June 2005.
- NHS to ensure that all mainstream hospital services are accessible to people with learning disabilities.
- Development of local specialist services for people with severe challenging behaviour to be a priority for the capital element of the Learning Disability Development Fund.
- Mental Health NSF will bring new benefits to people with learning disabilities.
- New role for specialist learning disability services, making most effective use of their expertise.

Reducing Health Inequalities

6.4 The NHS Plan made clear that inequalities in health cannot be tackled without dealing with the fundamental causes – including poverty, low educational attainment, unemployment, discrimination and social exclusion. These factors affect many people with learning disabilities, and their high morbidity and mortality rates show the importance of addressing their needs. The Government has launched a comprehensive plan to tackle health inequalities and work is taking place across Government to tackle the root causes.

6.5 The Government has announced that local health inequalities targets will be reinforced by the creation of national health inequalities targets, to be delivered by a combination of specific health policies and broader Government policies. Health policies such as improved access to services, smoking cessation, healthy diet and exercise will be particularly important for narrowing the gap between the health of learning disabled people and the population as a whole. In addition, health authorities should take account of the needs of learning disabled people in planning services and making them accessible to all.

6.6 Those who live and work with people with learning disabilities are well placed to encourage healthier life styles. Providers of support in social care settings have a responsibility for ensuring that an individual's general health needs are met, by developing links with health professionals, promoting family and staff competence in basic health issues and implementing health promotion initiatives.

6.7 The Government will ensure that policies on health inequality make explicit reference to people with learning disabilities. Health Action Zones, for example, should ensure that the needs of people with learning disabilities are being addressed within their areas when undertaking work to meet the needs of vulnerable people. Successful innovative learning disability work being led by HAZs should be identified and highlighted so that this can be mainstreamed and replicated elsewhere. Health Improvement Plans (HimPs) will provide a means of addressing the health needs of people with learning disabilities so that they do not experience avoidable illness and premature death.

6.8 Evidence of avoidable illness and premature death amongst people with learning disabilities is a major cause of concern for the Government. We will explore the feasibility of establishing a confidential inquiry into mortality among people with learning disabilities. This will help us take steps to reduce the number of avoidable deaths.

6.9 The Government will explore the possibility of developing performance indicators to compare the health status of the learning disabilities population with that of the general population. We shall consult on performance indicators later this year.

People with learning disabilities from minority ethnic communities

6.10 People with learning disabilities from minority ethnic communities are at particular risk of discrimination in gaining access to appropriate health care. Problems arise if professionals are not aware of cultural or language issues or only use English language based assessment tools. The NHS Plan recognises that ethnic minorities can face discrimination in gaining access to health services and confirms the Government's commitment to tackling the problem. Achieving this will be helped by the new statutory duty to promote race equality, in the Race Relations (Amendment) Act 2000. From 2 April 2001 listed public bodies, including central and local Government, the NHS and NHS Trusts, for example, will be obliged to work towards the elimination of unlawful racial discrimination and to promote good relations between persons of different racial groups. Staff who understand the values and concerns of minority ethnic communities and who can communicate effectively with them have an important role to play in ensuring that minority ethnic communities can access the health care they need.

Primary health care in Liverpool

'Speaking up' in public to doctors and nurses at a Primary Care Group Board was a new experience for self-advocates from the Toxteth and Granby Resource Centre, Liverpool. Some of the things they said were:

'We would like the same checks as everyone else'

'We want – you to explain and listen to us and not just talk to our carers; leaflets about health with pictures and get to know us as people and ask our point of view.

The result was an agreement to review primary care provision across the area.'

Meeting Health Needs

6.11 For most people, GPs, practice nurses and other members of primary care teams provide the main contact with the NHS. In future, we expect this to be the same for people with learning disabilities. Building on the guidance on good practice in primary care given in *Once A Day*, the primary care team will play a key role in providing health care for people with learning disabilities and in ensuring that people with learning disabilities can access the full range of health services to meet both their ordinary health needs and their additional health requirements through referral to specialist services. Primary care teams also have a key role in supporting and improving the health of carers.

Health Facilitators

6.12 As the first point of contact, primary care is the place where many important decisions are made. But for many people with learning disabilities their encounter with the primary care team may be frustrating and difficult. In order to overcome these barriers staff from the local community learning disability team in each area will need to take on the role of health facilitators to support people with learning disabilities to access the health care they need from primary care and other NHS services. This role might be taken up by any community learning disability team member, but learning disability nurses will be well placed to fulfil this role.

6.13 Health facilitators will help general practitioners and others in the primary care team to identify their patients with learning disabilities, in collaboration with colleagues from social services, education and health. Their task will be to facilitate, to advocate and to ensure that people with learning disabilities gain full access to the health care they need, whether from primary or secondary NHS services. The role of the health facilitators should embrace mental as well as physical needs. The health facilitator role will be vital in helping people with learning disabilities navigate their way around the health service.

6.14 All people with learning disabilities should be registered with a general practitioner. We expect that all general practices, with support from the health facilitator and in partnership with specialist learning disability services, will have identified all people with a learning disability registered with the practice by June 2004. Progress in achieving this objective will be monitored by the Department of Health.

Health Action Plans

6.15 The Government expects each individual with a learning disability to be offered a personal Health Action Plan (HAP). Responsibility for ensuring completion of the HAP will rest with the health facilitator in partnership with primary care nurses and general practitioners. The HAP will form part of the person-centred plan. The HAP is an action plan and will include details of the need for health interventions, oral health and dental care, fitness and mobility, continence, vision, hearing, nutrition and emotional needs as well as details of medication taken, side effects, and records of any screening tests.

6.16 Health Action Plans will be offered and reviewed at the following stages of peoples' lives:

- Transition from secondary education with a process for ongoing referral;
- Leaving home to move into a residential service;
- Moving home from one provider to another;
- Moving to an out of area placement;
- Changes in health status, for example as a result of a period of out-patient care or in-patient treatment;
- On retirement;
- When planning transition for those living with older family carers.

Anna has Down's syndrome. She uses a wheelchair and cannot communicate verbally. Her support team had difficulty in involving her in planning as she was lethargic, passive and difficult to motivate. A health care check revealed that she had undiagnosed thyroid problems, diabetes and hypertension. After treatment Anna became more involved, used her wheelchair less, and volunteered to help in a children's day centre.

6.17 The Government expects all Learning Disability Partnership Boards to have agreed a framework for the introduction of Health Action Plans and to have ensured that there are clearly identified health facilitators for all people with learning disability by June 2003. All people with learning disabilities should have a HAP by June 2005.

6.18 Primary Care Trusts in their commissioning role should ensure that general health care for people with learning disabilities is built into existing priorities. Partnership Boards need to work with the Primary Care Trusts to ensure that there is an integrated plan for supporting the primary and general health care services to work with people with learning disabilities, with clarity about expectations upon both general practice and general hospitals.

Secondary health care

6.19 Mainstream secondary health services must also be accessible for people with learning disabilities. There must be no discrimination. Support will be needed to help people with learning disabilities admitted to a general hospital for medical or surgical treatment to help them to understand and co-operate in their treatment. The NHS will ensure that all its procedures comply with the Disability Discrimination Act and that its staff recruitment and training practices are also fully compliant. Whenever possible NHS resources should be used to provide the appropriate health care support to enable people to live in their own home.

6.20 Health facilitators will have primary responsibility for facilitating access to secondary health care. But by 2002 a Patient Advocacy and Liaison Service (PALS) will be established in every NHS Trust. Individuals will then have an identifiable person they can turn to if they have a problem or need information while they are using hospital and other NHS services. Within the 130 or more NHS Trusts providing specialist health care for people with learning disabilities, PALS will have an especially important role for ensuring that people with learning disabilities can access the full range of NHS provision. PALS will complement the work of the health facilitator.

Consent to Treatment

6.21 The Government is committed to having good consent to treatment practice in place in all health settings. This is of particular importance in general hospitals where staff may be unfamiliar with seeking consent from people who have learning disabilities. The

Government has introduced changes to ensure that clearer guidance on consent issues is available and accessible.

National Service Frameworks (NSFs) and the National Cancer Plan

6.22 National Service Frameworks have already been published for mental health and coronary heart disease. NSF's for older people and for diabetes and for long term health conditions (including epilepsy) will follow. The National Cancer Plan which is now being implemented makes specific reference to the needs of people with learning disabilities. They will all apply equally to people with learning disabilities as to other patients and people with learning disabilities should benefit from all these initiatives.

THE NSF FOR MENTAL HEALTH – PEOPLE WITH LEARNING DISABILITIES

6.23 Most psychiatric disorders are more common amongst people with learning disabilities than in the general population. As for their other health needs, people with learning disabilities should be enabled to access general psychiatric services whenever possible. This will require mainstream mental health services to become more responsive, and specialist learning disability services to provide facilitation and support.

6.24 The NSF for Mental Health applies to all adults of working age. A person with a learning disability who has a mental illness should therefore expect to be able to access services and be treated in the same way as anyone else. The NSF for Mental Health seeks to integrate CPA (the Care Programme Approach) and care management. This should lead to a seamless service for people with learning disabilities who have mental health needs.

6.25 The Government will take steps to ensure that:

- Mental health promotion materials and information about services are provided in an accessible format for people with learning disabilities, including those from minority ethnic communities.
- Strategies for improving access to education, housing and employment which enhance and promote mental wellbeing will include people with learning disabilities and mental health problems.

- Clear local protocols are in place for collaboration between specialist learning disability services and specialist mental health services.
- For people with learning disabilities and mental health problems the Health Action Plan will equate with the Care Plan. Care co-ordinators should have expertise in both mental health and learning disabilities. There will be close collaboration between psychiatrists in the relevant specialities.
- Specialist staff from the learning disability service will if necessary provide support to crisis resolution/home treatment services or other alternatives to in-patient admission whenever possible.
- Each local service has access to an acute assessment and treatment resource for the small number of individuals with significant learning disabilities and mental health problems who cannot appropriately be admitted to general psychiatric services, even with specialist support.
- If admission to an assessment and treatment resource is unavoidable, specialist staff will help the patient understand and co-operate with treatment.

Tertiary Specialist Services

6.26 Referral to a tertiary specialist health service should be a rare event. However, there may be a small number of people who have complex health needs that cannot be met locally. For example, people who present very severe behavioural challenges may have needs for support and treatment which cannot be met within the skills and resources available locally. In the first instance the NHS provider should always work in partnership with the local authority to provide intensive support to sustain local provision. If individualised packages of housing and support are commissioned, they should be sited as close to a person's home area as possible. To facilitate this, we have made development of specialist services for people with severe challenging behaviour a priority for the use of the capital element of the Learning Disability Development Fund based on advice in the Mansell Committee Report.

Specialist Learning Disability Services

6.27 It is essential that sufficient good quality multi-disciplinary specialist services are available to meet the needs of people with learning disabilities. Locally based specialist community learning disability services are key components of the modern NHS. Over 130 NHS Trusts in England provide specialist services for people with learning disabilities. Through these NHS Trusts people with learning disabilities have access to a range of learning disability specialists including learning disability nurses, occupational therapists, physiotherapists, psychiatrists, speech and language therapists and clinical psychologists, working in a multi-disciplinary way in close collaboration with social workers and care managers. Other NHS professionals such as dieticians, psychotherapists and creative therapists, chiropodists, opticians, audiologists and pharmacists also have specialist roles.

6.28 The Government believes that professional staff employed in locally based specialist services provide vital support for people with learning disabilities. But their role must change. Staff may continue to work within specialist clinical directorates, but their tasks will need to be refocused to give greater emphasis to their role in providing high quality specialist expertise. They will also take on a key supplementary role in supporting people to access mainstream services.

6.29 Specialist services should be planned and delivered with a focus on the whole person, ensuring continuity of provision and appropriate partnership between different agencies and professions. To support these aims, services will need to demonstrate that they are listening carefully to the views and experiences of people with learning disabilities and their families, which should also play a critical part in the education and training of paid staff.

6.30 In their specialist role staff should recognise the importance of enhancing the competence of local services to enable service users to remain in their usual surroundings and save the often high costs (both personal and financial) of specialist placements out of area. Specialist staff will need to give more time to facilitating the work of others in mainstream services to developing the capacity of services to support those with complex needs to service design and less to direct interventions. Partnership Boards will review the role of specialist learning disability services to bring them into line with the new vision outlined here.

6.31 In addition to their clinical and therapeutic roles specialist staff should take on the following complementary tasks:

- a health promotion role; working closely with the local health promotion team;
- a health facilitation role; working with primary care teams, community health professionals and staff involved in delivering secondary health care;
- a teaching role; to enable a wide range of staff, including those who work in social services and the independent sector, to become more familiar with how to support people with learning disabilities to have their health needs met;
- A service development role; contributing their knowledge of health issues to planning processes.

Intensive Health Care Support

6.32 A proportion of people with learning disabilities will require intensive health care support through specialist community services, including learning disability teams and/or challenging behaviour teams, over a prolonged period of time – because of their complex disability or the challenges they place on services. Such people have the same entitlements to independence, choice, inclusion and civil rights as all others. The aim should be to provide them with ordinary housing and support services, in the least restrictive environment possible, with opportunities to lead full and purposeful lives.

6.33 Many people with such complex needs are currently living in community services as NHS in-patients. This is only appropriate where people require continuous medical supervision. A need for nursing supervision is not a sufficient reason for NHS in-patient care. Localities with large numbers of people living in such NHS accommodation should use person-centred planning and pooled budgets to design more appropriate locally based housing and support and so reduce the number of long term NHS in-patient beds to more appropriate levels. Forthcoming guidance on continuing care from the Department of Health will support this approach.

CHAPTER 7

HOUSING, FULFILLING LIVES AND EMPLOYMENT

This chapter sets out the Government's programme for reform in three areas which are of central importance in the lives of all people with learning disabilities: housing, living a fulfilling life, and employment. Bringing about change in all these areas will be essential in order to achieve greater independence, choice and inclusion for people with learning disabilities.

HOUSING

Government objective: To enable people with learning disabilities and their families to have greater choice and control over where and how they live.

Problems and Challenges

7.1 Most people with learning disabilities live with their families. Often they leave the family home only as the result of a crisis such as the illness or death of the carer. Planning ahead to move to more independent living is not always possible as the appropriate housing, care and support options may not be available. With growing numbers of people living with older carers, the Government wishes to see better forward planning by local councils so that carers do not face continuing uncertainty in old age and their sons and daughters gain greater independence in a planned way.

7.2 People with learning disabilities can live successfully in different types of housing, from individual self-contained properties, housing networks, group homes, and shared accommodation schemes, through to village and other forms of intentional community. They can cope with the full range of tenures, including home ownership.

David inherited the tenancy of a housing association bungalow following his mother's death. He has a support package from a care provider and had some intensive support from the Community Team for Learning Disabilities to improve his cooking and domestic skills. His brother and sister-in-law live nearby and provide emotional and practical support. He is now coping well.

Expanding the range and choice of housing, care and support services is key to giving individuals more choice and control over their lives.

7.3 Few areas offer a full range of options. Obstacles include:

- A culture of professionals deciding what is good for individuals, and the traditional "take what you are given" attitude in public provision of housing;
- A conservatism in developing housing options for people with learning disabilities, with authorities replicating current provision rather than taking opportunities to broaden the range of housing available.

7.4 We now know more about outcomes associated with living in different types of accommodation. Research commissioned by the Department of Health examined the differences in cost and benefits between dispersed housing, NHS residential campuses, and village communities.[11] It found dispersed housing and village communities had strengths and weaknesses: dispersed housing was associated with greater personal choice, greater participation in community activities, wider personal relationships, and better qualified and more senior staff; village communities were associated with better activity planning, more routine day activities, better access to health checks, and less likelihood of exposure to crime or verbal abuse. There were many areas where no significant difference was found, including cost. Living in NHS residential campuses produced significantly poorer outcomes.

7.5 Various studies showed that housing design on its own does not guarantee positive outcomes. Factors such as management style and staff training are at least as important. In view of this, the Government wishes to encourage development of a range of housing options and, thus, provide real choice to people with learning disabilities and their families. No housing solution should be routinely disregarded as a matter of deliberate policy. The role of public services is to facilitate choice, not frustrate it.

7.6 Widening the housing, care and support options available creates the potential for choice, but individuals also need accessible information in order to make choices. Many people with learning disabilities will need advice and support to do this.

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[11] The Quality and Costs of Residential Support for People with Learning Disabilities, Summary & Implications (Hester Adrian Research Centre, University of Manchester, 1999

What More Needs To Be Done

KEY ACTIONS – HOUSING

- Housing and social services to work together to expand housing, care and support options: Department of Health and Department of the Environment, Transport and the Regions to issue new joint guidance in 2001.
- Legislation to introduce new duty on local housing authorities to provide advice and information.
- Learning Disability Partnership Boards to develop local housing strategies for people with learning disabilities.
- Learning Disability Development Fund will prioritise "supported living" approaches for people living with older carers.
- Enabling people living in the remaining long-stay hospitals to move to more appropriate accommodation by 2004 will be a priority for the Learning Disability Development Fund.

Options and Choices – Barnet

Housing and social services work together and benefit from this joint working. Social services keep an up to date list of priority cases for housing and accommodation needs. An annual quota for nominations for housing association or council lettings was jointly managed with the housing department agreeing eligibility for housing. By 1999 this had changed the range of services from one which was predominantly registered residential care to one where more than a hundred people had their own tenancy and were receiving housing benefit.

Expanding Choice in Housing, Care and Support Services

7.7 The Housing Green Paper (April 2000) set out the Government's agenda for improving the quality and choice of housing available to all. Its proposals, such as more open housing access and choice based lettings procedures, apply as much to people with learning disabilities as to other people. We are also removing other obstacles and barriers to expanding housing, care and support options by putting in place new policies and tools to create the environment and the imperative for local action.

7.8 Local housing authorities have a key role to play through their work to develop and implement local housing strategies and by providing housing advice and improving access to housing. However, they can only succeed in expanding the housing choices available to people with learning disabilities by working in partnership with social services, health and other local agencies.

7.9 In order to strengthen such partnerships, the Department of Health and the Department of the Environment, Transport and the Regions will shortly issue a joint circular and detailed guidance on commissioning the range of housing, care and support services required to expand housing choice. This will include consideration of ways to develop new joint performance indicators for social services and housing authorities.

7.10 In England there are over 4 million existing homes in the social rented sector alone. These, together with private sector housing, are potential resources that can be drawn on to open up housing, care and support options for people with learning disabilities. The Government is also making available over £10 billion of housing capital resources over the next three years to be drawn upon to finance remodelling of existing housing or new development.

7.11 The Government expects local councils to give people with learning disabilities a genuine opportunity to choose between housing, care and support options that include:

- **Supported living:** this approach is concerned with designing services round the particular needs and wishes of individuals and is less likely to result in housing and support that is designed around congregate living. Department of Health research has shown that supported living is associated with people having greater overall choice and a wider range of community activities.
- **Small scale ordinary housing:** Department of Health research has shown that small scale ordinary housing is likely to lead to better outcomes across a range of factors than is large housing or hostel provision.
- **Village and intentional communities:** These comprise houses and some shared facilities on one or more sites. Department of Health research shows such communities were associated with better activity planning, more routine day activities and better access to health checks. A study commissioned as part of the White Paper's development found 3,000 people living in 73 village and intentional communities. This study and *Facing the Facts* also indicated that some local authorities are reluctant to support people with learning disabilities who wish to live, or whose families make arrangements for them to live, in a village or intentional community.

7.12 The Government will issue statutory guidance to local councils to ensure they do not rule out any of these options when considering the future housing, care and support needs of people with learning disabilities and their families.

Supporting People

7.13 *Supporting People* is a new policy and funding framework for support services that will be implemented in April 2003. It will bring together resources from several existing programmes into a new grant to local authorities, which can be applied more flexibly to fund support services for people with learning disabilities and for other vulnerable people wherever they live. Local social services and housing authorities, working with other partners including the NHS, will be expected to establish joint arrangements for deciding how to apply the new grant and to integrate the planning and commissioning of support services with the planning and commissioning of housing, care, and health services.

Housing Advice and Assistance

7.14 Legislation to enable local authorities to introduce choice based letting systems for access to social housing is currently before Parliament. The provisions include a new duty on local housing authorities to provide assistance to people, including those with learning disabilities, who need help when applying for and obtaining social housing. Local authorities will have flexibility as to how this is provided, and how far they integrate it with their wider advice and advocacy services for people with learning disabilities.

Local Housing Strategies

7.15 Learning Disability Partnership Boards will be expected to ensure that they set out plans for the provision of information, advice and advocacy services covering the different aspects of individuals' needs, including housing, as part of the Learning Disability Joint Investment Plan (JIP). This requires the participation of housing authorities in the development of the Learning Disability JIP, and in the planning and development of services. Likewise, social services and the NHS need to be involved in developing the local housing strategy and Housing Investment Programmes. At operational level, links need to be made between local housing authorities' housing advice services and local arrangements for accessing housing, and wider person-centred planning processes for people with learning disabilities. Joint Investment Plans provide an opportunity for all stakeholders to review the housing care and support options available in their area and develop plans for how to expand choice for individuals.

People Living with Older Carers

7.16 The Government recognises that there is particular concern about the position of people with learning disabilities living with older carers aged 70 and over. They and their families need to be able to plan for the future in good time. We have therefore decided to make promoting supported living for this group of people with learning disabilities one of the priorities both the revenue and capital elements of the Learning Disability Development Fund.

The NHS as Housing Provider

7.17 For almost 30 years, successive Governments have been committed to the reprovision of long-stay hospital accommodation in order to enable people to live in community-based housing. However, there remain over 1500 people living in old long-stay hospitals. In some areas, the long-stay hospitals have been partly replaced by NHS residential campuses often on former hospital sites or in NHS homes in the community. There are about 1500 people, outside the hospitals, who remain as patients under the care of a consultant in the NHS. Research has raised significant concerns about the quality of life enjoyed by people living in NHS residential campuses developed as a result of the contraction or closure of NHS hospitals.

7.18 While people with learning disabilities, like other people, may need to be admitted to hospital on a short-term basis, we do not believe it is right for them to live in NHS hospital accommodation on a long-term basis. The Government will enable all people currently living in long-stay hospitals to move into more appropriate accommodation by April 2004. Learning Disability Partnership Boards should therefore work together to agree and implement alternative housing, care and support plans for such people in order to achieve closure of those hospitals by this date. This will be a priority for the revenue element of the Learning Disability Development Fund.

7.19 In the case of residential campuses and retained beds, Partnership Boards should agree a timetable for extending person-centred planning (to commence by October 2002) to all people currently living there. This will inform discussions with the person and their family to decide whether alternative community-based housing, care and support options would be in their best interests. Where they are, these alternatives should be made available. Where people wish to remain in NHS residential campuses, Partnership Boards will be expected to monitor and improve the quality of care they receive.

FULFILLING LIVES

Government Objective: To enable people with learning disabilities to lead full and purposeful lives within their community and to develop a range of friendships, activities and relationships.

Problems and Challenges

7.20 At present many people with learning disabilities do not take part in community activities or participate in wider social networks with non-disabled people. Few have friends apart from those paid to be with them, their close family, or other people with learning disabilities with whom they live. Being part of the local community benefits everyone. This chapter sets out the action the Government will take to help promote social inclusion for people with learning disabilities.

KEY ACTIONS – FULFILLING LIVES

- Five year programme to modernise day services by 2006 – priority for the Learning Disability Development Fund.
- Learning and Skills Council to ensure equal access to education.
- Action to outlaw discrimination against people with learning disabilities on public transport.
- Leisure plans to incorporate the needs of people with learning disabilities.
- New initiatives to improve services for parents with a learning disability
- Improved disability awareness training for Department of Social Security staff administering Disability Living Allowance.

Modernising Day Services

7.21 For decades, services for people with learning disabilities have been heavily reliant on large, often institutional, day centres. These have provided much needed respite for families, but they have made a limited contribution to promoting social inclusion or independence for people with learning disabilities. People with learning disabilities attending them have not had opportunities to develop individual interests or the skills and experience they need in order to move into employment.

7.22 Local councils currently spend over £300 million a year on day services of which more than 80% goes on over 60,000 day centre places that often focus on large, group activities. The most severely disabled people often receive the poorest service and the particular cultural needs of people from minority ethnic communities are too often not addressed.

7.23 Some local councils have done much to modernise their day services, but overall progress has been too slow. The barriers standing in the way of change include:

- Difficulties in releasing resources tied up in buildings and staff;
- Slow development of links with other services (including supported employment) and support in the wider community;
- Tension between providing respite for families and fulfilling opportunities for the person;
- Slow progress in introducing person-centred approaches to planning.

7.24 The Government wishes to see a greater emphasis on individualised and flexible services which will:

- Support people in developing their capacity to do what they want;
- Help people develop social skills and the capacity to form friendships and relationships with a wider range of people;
- Enable people to develop skills and enhance their employability;
- Help communities welcome people with learning disabilities.

7.25 These problems will be addressed through a five year programme to support local councils in modernising their day services. Our aim will be to ensure that the resources currently committed to day centres are focused on providing people with learning disabilities with new opportunities to lead full and purposeful lives. Securing the active involvement of people with learning disabilities and their families in redesigning services will be essential to the success of the programme. The Government recognises that, for many families, day centres have provided essential respite from the day to day demands of caring. The services that replace them must result in improvements for both users and their families. The needs of people with profound or complex disabilities will be carefully considered as part of the modernisation programme.

Sawston and Bottisham, Cambridgeshire

A group of people with learning disabilities won the bid to keep the vending machines in the local college filled. Another group bid to win the contract to keep the village tidy. A strong partnership with the Village College in Sawston provided a base and opportunities to participate in a range of courses. A local charity funded a job coach, so people had opportunities for individualised employment. This meant that people did not have to be bused into Cambridge to a large day centre.

7.26 Modernising day services will involve developing and strengthening links with local supported employment schemes, and with providers of further and community education and training for disabled people. The Government recognises the need to strengthen these relationships further at national level.

7.27 Day services should be modernised by 2006. Learning Disability Partnership Boards will be required to draw up modernisation programmes by 2002 for achieving this. Plans will address the future role of existing large day centres. The introduction of person-centred planning for people using day centres will be a key element for achieving this. People using them should be an early priority for person-centred planning.

7.28 Modernising day centres will be one of the priority areas for the Learning Disability Development Fund, in order to provide bridging finance to support change. The Implementation Support Team will give early priority to supporting day service modernisation.

Education and Lifelong Learning

7.29 Many people with learning disabilities make use of further education provision, Local Education Authority adult and community education and adult work-based training opportunities to develop and extend their skills. They need to have the same access as other people to opportunities for education and lifelong learning.

7.30 We recognise the importance of meeting the learning needs of people with learning disabilities through a person-centred approach. Young people in particular should not be sent to further education colleges because there is a lack of suitable provision either in updated training facilities or in supported employment. The Learning and Skills Act 2000 gives the Learning and Skills Council (LSC) specific responsibility to have regard to the needs of young people and adults with learning disabilities when securing post-16 education and training. The LSC is required to:

- Make arrangements to ensure that young people and adults with learning disabilities have access to provision which meets their needs and, where appropriate, to additional support;
- Build equality of opportunity into its policies, programmes and actions, working closely with key equality organisations including the Disability Rights Commission;
- Have regard to the needs of learners with learning difficulties when providing work experience.

The Department for Education and Employment will be working with Skill, the National Bureau for Students with Disabilities, to prepare a statement of good practice on the practical steps institutions should take to enable students to gain access to suitable places and successful work experience there.

7.31 In addition, the Government has announced that £172 million in the post-16 sector (Further Education, Higher Education, Adult Education and the Youth Service) will be used over the period 2002/03 to 2003/04 to improve accessibility for disabled students and adult learners in England. The new Adult Basic Skills Strategy Unit, based in the Department for Education and Employment, will oversee literacy and numeracy developments at national and regional level and act as a catalyst to initiate action by others to improve people's basic skills. The Unit is funding a £1.5 million project to develop ways of improving literacy and numeracy among people with learning difficulties and/or disabilities.

7.32 The Learning And Skills Act 2000 also established Local Learning Partnerships which will have a key role to promote learning and ensure it meets the needs of local communities. These Partnerships will ensure:

- effective consultative mechanisms are in place so that the views of people with learning disabilities are heard by providers and the LSC;
- the content of and access to local learning provision meet the needs of people with learning disabilities.

7.33 The Special Educational Needs and Disability Bill currently before Parliament will remove the current exemption of education from disability rights legislation and give people with disabilities new rights in Local Education Authority (LEA) adult and community education, further education, higher education institutions and LEA youth service provision. It aims to ensure that disabled students, including those with learning disabilities, are not treated less favourably than non-disabled students. Post-16 institutions will have to make reasonable adjustments to their premises to ensure that disabled students are not put at a substantial disadvantage to their peers. The Bill will make it unlawful for institutions to discriminate against disabled people not only in the way they carry out their main business – the provision of education – but also in arranging admissions and providing wider services, such as accommodation, welfare services, and careers advice.

Transport

7.34 Access to transport is essential to enable people with learning disabilities to lead full and purposeful lives. However, they currently face many obstacles using public or private transport. Transport staff and operators may not understand their needs and people may lack the necessary support and training to become independent travellers.

7.35 The Department of the Environment, Transport and the Regions (DETR) is committed to working closely with people with learning disabilities and the transport industries to identify and meet the transport needs of people with disabilities. Government measures to improve access to transport for disabled people already taken or under way include:

- Implementation of the transport provisions in the Disability Discrimination Act;
- Development of disability training packages by the transport industry (supported by DETR);
- Greater emphasis on meeting the transport needs of disabled people, including those with learning disabilities, through Local Transport Plans;
- Increased focus on learning disability in the membership and agenda of DETR's Disabled Persons Transport Advisory Committee.

7.36 DETR will consult on proposals for legislation to outlaw discrimination against disabled people, including those with learning disabilities, on public transport and will monitor the effectiveness of local authority responses to meeting the needs of disabled people in the Local Transport Plans.

Heart'n'Soul – a national touring company of 10 people with learning disabilities and 4 professional musicians-was founded in 1986. It is based in the Albany Theatre London. The company has forged a name for itself on the international stage with performances. They run the Beautiful Octopus Club – a night club run and organised by people with learning disabilities. It has toured with 10 full scale musical productions and produced *Breaking the Rules*, its own half-hour television programme for BBC2.

Leisure and Relationships

7.37 People with learning disabilities often do not take part in ordinary leisure activities. Leisure is rarely built into individual or community care plans. It tends to be seen as an optional extra, generally coming well down the list of agencies' priorities when decisions are being made about resources. Enabling people to use a wider range of leisure opportunities can make a significant contribution to improving quality of life, can help to tackle social exclusion, and encourage healthy lifestyles.

7.38 The Government expects local councils to ensure that their local cultural strategies and service plans encompass the needs of people with learning disabilities. This will include a review of physical access to leisure resources and ways to find out about them. Leisure will be an integral part of person-centred planning.

7.39 People with learning disabilities are often socially isolated. Helping people sustain friendships is consistently shown as being one of the greatest challenges faced by learning disability services. Good services will help people with learning disabilities develop opportunities to form relationships, including ones of a physical and sexual nature. It is important that people can receive accessible sex education and information about relationships and contraception.

Parents with a Learning Disability

7.40 The number of people with learning disabilities who are forming relationships and having children has steadily increased over the last 20 years. Parents with learning disabilities are amongst the most socially and economically disadvantaged groups. They are more likely than other parents to make heavy demands on child welfare services and have their children looked after by the local authority. People with learning disabilities can be good parents and provide their children with a good start in life, but may require considerable help to do so. This requires children and adult social services teams to work closely together to develop a common approach. Social services departments have a duty to safeguard the welfare of children, and in some circumstances a parent with learning disabilities will not be able to meet their child's needs. However, we believe this should not be the result of agencies not arranging for appropriate and timely support.

7.41 Support for disabled parents, including those with learning disabilities, is patchy and underdeveloped, as confirmed in the Social Services Inspectorate inspection *A Jigsaw of Services*[12]. There are tensions and even conflicts within social services departments between those whose focus is the welfare of the child and those concerned with the parent.

7.42 The Government's Framework for the Assessment of Children In Need and their Families is intended for use with all children in need and their families. Further work is needed to help staff use the Assessment Framework when working with parents with learning disabilities and ensure that assessments result in appropriate services being provided to the child and their family. The Department of Health will commission the development of training materials to

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12 Department of Health, (2000) (CI (2000) 6) Social Services Inspectorate Inspection: A Jigsaw of Services: Inspection of services to support disabled adults in their parenting role

assist in this process. Parents with learning disabilities will be a priority for follow-up work on the Assessment Framework. We shall also ensure that their needs and those of their children are addressed in future Quality Protects initiatives. The Department of Health will work with Sure Start and the National Parenting Institute to ensure that the needs of parents with learning disabilities are recognised within the Government's wider initiatives to improve parenting and family support.

7.43 At local level, it will be the responsibility of the Director of Social Services, as part of his/her responsibilities for ensuring quality under the social care Quality Framework to ensure effective partnership working for parents with learning disabilities between children's and adult's teams. Partnership Boards should ensure that services are available to support parents with a learning disability.

Social Security Benefits

7.44 For many learning disabled people, the social security system represents their main source of income. Only a small proportion are in paid employment and they are likely to be receiving benefits as well. The main benefits that learning disabled people receive are Income Support, Severe Disablement Allowance (SDA) and the Disability Living Allowance (DLA). They make up a significant proportion of the caseload for SDA (nearly a fifth) and DLA (10%).

7.45 A high proportion of decisions on DLA (Disability Living Allowance) are currently subject to successful challenge on appeal – around 46% for all cases and higher for cases involving some learning disabilities. The Government recognises the importance of ensuring consistency in decisions on entitlement. The Department of Social Security is developing a training programme for delivery to all staff, designed to lead to improvements in the quality of service provided to disabled people and their carers.

7.46 The Government is aware of concerns that attempting work or training will affect entitlement to DLA. Entitlement is assessed on a person's need for help with personal care and/or difficulty in getting round. People in work (see also paragraph 7.64) can receive DLA and evidence suggests that for many disabled people who work, this benefit provides important support. Indeed, some disabled people would not be able to work without the additional help and support provided by DLA.

7.47 Benefit decision makers are encouraged not to assume that starting work inevitably means that the severity of disabilities has reduced. Hard and fast rules are inappropriate, since some disabled people may require more support after starting work. The Department of Social Security has issued new guidance on this matter to benefit decision makers and is committed to keeping it under review. This should ensure that disabled people starting work do not lose their DLA without strong and sufficient reason. Complaints have reduced significantly since the guidance was improved.

7.48 The benefits system needs to keep pace with changes in society and the economy generally. The Government will shortly be introducing some changes to improve support for people with long-term sickness or disabilities, who rely on social security benefits:

- From April 2001, young people disabled before the age of 20, many of whom will have learning disabilities, will be able to qualify for Incapacity Benefit, without having to satisfy the normal contribution conditions. This age limit is extended to 25 for young people in education or work-based training immediately before the age of 20. From April 2002, these young people will get up to £27.60 a week extra from Incapacity Benefit (2001 benefit rates).
- A new premium in the income-related benefits will deliver, from April 2001, increased incomes for adults under 60 with severe disabilities and the greatest care needs who are on the lowest incomes. The Disability Income Guarantee will ensure an income of at least £142.00 a week for a single person and £186.60 for a couple. A new enhanced disability tax credit will be introduced to deliver equivalent increases within Working Families Tax Credit and Disabled Persons Tax Credit.

7.49 The Department of Social Security has a programme of work to help disabled people access benefits, including material for people who have difficulty using standard products. These are mainly targeted on clients who are visually impaired. It has also concluded that the best way to provide benefit information to people with learning disabilities and their carers is on a one-to-one basis. However the Department of Social Security plans to consult further about the most effective ways of communicating with people with learning disabilities and their carers to identify whether specially designed material would be effective.

MOVING INTO EMPLOYMENT

Government Objective: To enable more people with learning disabilities to participate in all forms of employment, wherever possible in paid work, and to make a valued contribution to the world of work.

7.50 The Government believes that employment is an important route to social inclusion and that all those who wish to work should have the opportunities and support to do so. Our Welfare to Work agenda is designed to increase employment opportunities for those who can work while retaining support for those who are unable to work. We will ensure that people with learning disabilities benefit from this major programme of reform.

Problems and Challenges

7.51 Disabled people are amongst those in our society with the lowest employment rates. It is likely that less than 10% of people with learning disabilities are in employment. Paid employment will not be a realistic option for all those with learning disabilities, but real jobs with real wages are a major aspiration for many people.

7.52 The reasons for this exclusion from the labour market are complex, but they include:

- Low expectations on the part of many agencies and professionals of what people with learning disabilities can achieve. This has meant that many learning disabled young people have not received training and preparation for employment. Services working with adults with learning disabilities have not seen helping them find work as a priority;
- The interaction between social security benefit rules and employment can result in disincentives to work for some learning disabled people;
- Difficulties in progressing from supported employment schemes (where these exist) into mainstream employment.

7.53 The Government is committed to helping more people with learning disabilities develop the skills they need to move into the labour market. Employment has the potential to improve people’s financial situation, open up another source of friends and social contact and increase people’s self-esteem.

What More Needs To Be Done

KEY ACTIONS – MOVING INTO EMPLOYMENT

- New Government target for increasing numbers of people with learning disabilities in work.
- New Workstep Programme will benefit people with learning disabilities.
- Joint Department of Health/Department for Education and Employment scoping study into links between supported employment and day services.
- Job Brokers under the New Deal for Disabled People will have skills in working with people with learning disabilities.
- Disabled people starting work will not lose Disability Living Allowance unfairly.
- Learning Disability Partnership Boards to develop local employment strategies.
- Better employment opportunities in public services for people with learning disabilities.

New Targets and Incentives

7.54 The Government's overall aim is to increase the number of people with learning disabilities in employment and to work towards their achieving parity with other disabled people in the workforce. Our target for this group is to increase the employment rate of people with learning disabilities and reduce the difference between their employment rates and the overall employment rate of disabled people. The challenge now is to ensure that our programmes and policies reach as many people with learning disabilities as possible and are delivered in ways which are responsive to their needs. The Government will work with the Employers Forum on Disability and the local Employer Networks to ensure that employers are engaged in this process.

7.55 The Government has taken a number of important steps to improve the incentives for moving into employment, including introduction of the minimum wage and the Disabled Person's Tax Credit which will help to achieve our target. We recognise that the interaction between benefit rules and income from employment can result in

Steven's Story

After Steven left school he went to an Adult Training Centre every day. By the age of 26 he felt ready to look for work. A trial work placement in a local garage was arranged. The owner realised Steven could locate and assemble parts into organised pre-assembly kits efficiently and accurately. Steven has now developed into a skilled and valued member of staff. 10 years later he is still working there on the assembly line with complex parts and production techniques.

disincentives for disabled people. Various measures have been introduced to address this, including:

- The improved Incapacity Benefit linking rule allows people to re-qualify for benefits if they move into work or employment training, but fall ill again and return to benefit within a year (two years if they move on to Disabled Persons Tax Credit);
- The higher earnings disregards in the Independent Living Fund for those of their clients who wish to work;
- From April 2001, the earnings disregard in income-related benefits will rise from £15 to £20 a week for disabled people and other special groups including carers.

Workstep: Reforming the Supported Employment Programme

7.56 Supported employment is provided by a variety of agencies including the voluntary sector, local authorities (usually via social services departments), and health authorities and through the Government's Supported Employment Programme. Many using supported employment are people with learning disabilities and in one form or another supported employment has traditionally been the main route to employment for people with learning disabilities.

7.57 A recent report by the Policy Consortium for Supported Employment takes stock of current provision and concludes that there is scope for considerable development in this sector. The report identifies barriers to the expansion of supported employment and proposes possible ways of tackling them.

7.58 The Government's Supported Employment Programme is operated by the Employment Service. Over 22,000 disabled people are employed at a cost of over £155 million including over 10,000 people employed by Remploy and over 12,000 people employed through Supported Employment Programmes (SEP) run by local authorities and voluntary bodies. Some 40% of those on SEP have learning disabilities – the highest single category of disability.

7.59 The Government is modernising the programme. From April 2001 it will be renamed Workstep and it will have greater focus on developing disabled people and helping them move into mainstream employment where they wish to do so and with longer term support available where needed. The aim for progression will be 10% a year for existing supported employees and 30% over two years for new supported employees. This figure may be adjusted once we have more information on which to base it. The evaluation of the programme will look at its impact on people with learning disabilities.

Links between Supported Employment and Day Services

7.60 The Government recognises that we need to look more closely at the interface between the full range of pre-vocational, employment and supported employment provision, including Department for Education and Employment's Workstep, and day services provided by local councils and the health service. The Department for Education and Employment and the Department of Health will establish a joint working group to explore this issue further, in partnership with local authorities and the voluntary sector. The two Departments will also jointly fund a scoping study to look at these issues in more depth. The outcome from this work will help the Learning Disability Partnership Boards in drawing up their plans to modernise day services.

The Working Age Agency

7.61 From summer 2001, the services currently delivered by the Employment Service and Benefits Agency will be brought together in the new Working Age Agency. This will allow for delivery of a more integrated and efficient service. It will be important that frontline staff in the new Agency have the right skills and training to work with people with learning disabilities. An appropriate training programme will be developed.

New Deal for Disabled People (NDDP)

7.62 The New Deal for Disabled People- the joint initiative between the Department of Social Security and the Department for Education and Employment – has been testing a range of approaches to find out how best to help disabled people who want to work. By the end of December 2000 the NDDP pilots had helped over 6,000 disabled people into work. NDDP will be extended nationally from July 2001, building on experience in the pilot phase. The development of a network of job brokers to offer work focused help to disabled people will be a central feature.

James's Story

James started working at Leeds United last season, a club for which he holds a season ticket. This is his first paid job, which means he can spend money on his other hobby- music. Before he had to save for weeks to buy CDs. When he started working, he received full training on which chemicals to use when cleaning and how to handle them. The training was tailor made so that he could recognise the different bottles easily. It was easiest for him to remember the pictures on the bottles and their colours. In the past people might say horrible things to James, which easily undermined his confidence. But he says that since he's been working it's really boosted his confidence. He's good at this job and so now has more responsibility overseeing different areas of work. He's made lots of friends since he started working, feels a sense of belonging and loves his job.

7.63 The Department for Education and Employment will ensure that the new job brokers have the skills needed to work with people with learning disabilities. Organisations bidding to be job brokers will need to have the right capacity and competences. Arrangements will be set up for sharing good practice and ensuring on-going strong performance by job brokers in this area. All organisations and individuals who work with disabled people must provide the support and advice they need to make appropriate decisions and be sensitive to the needs of people with learning disabilities. We will be looking to see what additional training and advice needs to be put in place.

The Disability Living Allowance (DLA)

7.64 As mentioned in paragraphs 7.46 and 7.47 this benefit provides important support for many disabled people who work. Disabled people in work can receive DLA and benefit decision makers are encouraged not to assume that starting work inevitably means that the severity of disabilities has reduced.

Local Employment Strategies

7.65 Local councils have been asked to have Joint Investment Plans for Welfare to Work for Disabled People in place by April 2001. This is an important tool for improving the range of local employment opportunities. In many areas, preparatory work for the Welfare to Work Joint Investment Plans has done a good deal to strengthen relationships between local councils and the Employment Service in order to increase employment opportunities for disabled people. The Government intends to build on these emerging links. Local Employment Services will be members of the Learning Disability Partnership Boards, and will play an active part in developing local employment strategies. These will include local targets for the employment of people with learning disabilities. Partnership Boards will also be expected to identify employment champions.

Better Employment Opportunities in the Public Sector

7.66 Central Government, local government and the NHS together form one of the largest employment groups in the world. A small minority within the public sector employ people with learning disabilities, but currently very few are employed in real jobs in either central or local government or the NHS.

7.67 The Government is committed to a dramatic improvement in diversity with the Civil Service, including the employment of disabled people. We will seek to improve our employment of people with learning disabilities as part of this process.

7.68 The Department of Health is committed to widening opportunities for employing disabled people, including those with learning disabilities, in the NHS. Local councils will be setting targets for the employment of socially excluded people, including people with learning disabilities, as part of Local Public Service Agreements.

CHAPTER 8

QUALITY SERVICES

8.1 The Government is committed to raising standards and improving quality in services for people with learning disabilities. Good quality services that promote independence, choice and inclusion will lead to good outcomes for people with learning disabilities. This chapter covers quality, workforce training and planning, resources and people with additional needs. The last topic covers services for people with profound and complex disabilities, people suffering from the autistic spectrum disorder; people with challenging behaviour, and people developing conditions associated with old age. These groups have additional and complex needs and achieving good quality services for them requires greater skill and effective co-ordination

QUALITY

Government Objective: To ensure that all agencies commission and provide high quality, evidence-based and continuously improving services which promote both good outcomes and best value.

Problems and Challenges

8.2 Quality assurance in learning disability services is currently underdeveloped. Few places have achieved a holistic approach that systematically draws on all sources of information and research, including feedback from users. Complaint procedures are often inaccessible. People from minority ethnic communities are too often at the margins of services and funding, and people with learning disabilities do not always receive adequate protection from abuse and exploitation. The challenge for agencies working in the learning disability field will be to:

- develop a better approach to measuring quality, which emphasises improved outcomes as informed by the best quality research;

- work in partnership with other agencies in developing benchmarks for measuring performance;
- enable people with learning disabilities to lead lives safe from harm and abuse;
- put the needs and wishes of the person using the service at the centre of their quality assurance systems.

What More Needs To Be Done

KEY ACTIONS – QUALITY

- National Minimum Standards for residential care for people with learning disabilities.
- Social Care Institute of Excellence to be leading source of expertise in learning disability informed by high quality research evidence base.
- Local quality assurance frameworks to be in place by April 2002.
- Department of Health guidance issued on user surveys in 2001.
- Local councils to collect information about incidents of abuse.
- DH guidance on physical interventions with people with learning disabilities in 2001.
- Measures to assist vulnerable or intimidated witnesses give evidence in court.

Care Standards Act 2000

8.3 The Care Standards Act 2000 introduces major changes to registration and inspection. It establishes a new regulatory framework for social care which will improve protection and raise standards for people with learning disabilities who use care services. The National Care Standards Commission (NCSC), which will come into operation from April 2002, will be responsible for ensuring that all regulated care services, including those managed by local councils, are provided to national minimum standards laid down by the Secretary of State. The Department of Health will be consulting on draft regulations and national minimum standards for care homes, adult placements and domiciliary services.

The Social Care Institute of Excellence (SCIE)

8.4 The Government is setting up the Social Care Institute of Excellence which will contribute to improvements in learning disability services by promoting evidence based practice to address the current variation in quality. The Department of Health will ensure that SCIE is properly equipped to become a leading voice in learning disability. SCIE will consult people with learning disabilities and their carers about guidelines on what works and produce their work in an accessible format.

Local Quality Frameworks

8.5 The new Quality Framework for Social Care – set out in *A Quality Strategy for Social Care* – and clinical governance in the NHS – set out in *A First Class Service* – together provide a means of promoting high quality services for people with learning disabilities. As part of their responsibilities under the Quality Framework, we expect Directors of Social Services to ensure that their local quality systems recognise and address the needs of people with learning disabilities. Given the importance of close integrated working for learning disability services, the Learning Disability Partnership Board will need to ensure the development of an integrated quality framework that applies across all agencies. This should make people with learning disabilities its central focus with their voices clearly heard and services clearly accountable to them.

8.6 An inter-agency quality assurance framework should be in place by April 2002.

User Surveys and Complaints Procedures

8.7 The Government expects people with learning disabilities and their carers to be fully involved in planning, monitoring and reviewing services; and also in evaluating the quality of the services they receive, as required under the new Quality Framework for Social Care. Local councils need to have a clearer picture of the experience of all users and carers who receive social care services, including hard to reach groups such as people with learning disabilities. The Department of Health will be issuing guidance in September 2001 to help local authorities improve the way they use and carry out surveys.

8.8 The Government believes that complaints procedures should be more accessible to service users and their carers. The Department of Health is currently considering ways of improving social services complaints procedures, including their accessibility. The NHS Plan commits the Government to reforming the NHS complaints procedures; the intention is to consult on proposals later this year.

Minority Ethnic Communities

8.9 The Government has identified many ways in which services and support to people with learning disabilities from minority ethnic communities are failing to meet the needs of individuals and their families. There are a small number of innovative initiatives across the country. These are not widespread and the Government expects all agencies to improve their practice to fulfil the objectives of the NHS Plan and legal obligations set out in the Race Relations (Amendment) Act 2000. Learning Disability Partnership Boards, which will largely be drawn from bodies which are subject to the new duty to promote race equality in the performance of their functions, should ensure that local services are culturally competent and can meet all the cultural needs of their communities.

Imran's Story

Imran lives with his family, whose concerns for his welfare made them reluctant to introduce him to activities outside the home. Since becoming involved in a community-based group for Asian people with disabilities, he has grown in confidence and independent living skills. His family has developed more trust in what he can gain from an outside environment. Imran now has financial independence through his skills as an entertainer. He is often asked to perform at local and city-wide events and is a popular member of his community.

Protecting Vulnerable Adults

8.10 People with learning disabilities are entitled to at least the same level of support and protection from abuse and harm as other citizens. This needs to be provided in a way which respects their own choices and decisions. Good quality services for people with learning disabilities must support them to lead lives safe from harm and abuse, whilst enabling them to lead fulfilling lives. The Department of Health's No Secrets guidance sets out a framework for the protection of all vulnerable adults that will provide important safeguards for people with learning disabilities. Local councils with social services responsibilities should take the lead in developing local policies and procedures for the protection of vulnerable adults within an inter-agency framework, which may be supported by the establishment of a multi-agency management committee.

8.11 Local councils will need to ensure that learning disability services are represented on local adult protection management committees, and that information about incidents of abuse of people with learning disabilities is gathered and recorded.

Vulnerable Witnesses

8.12 Although measures are in place to assist child witnesses, many adult victims and witnesses find the criminal justice process daunting and stressful. Some witnesses are not always regarded as capable of giving evidence and so can be denied access to justice. This can include people with learning disabilities.

8.13 In June 1998 the Government published the report *Speaking up for Justice*, which made 78 recommendations to assist vulnerable or intimidated witnesses, including children, give evidence in court and so improve their access to justice. Those recommendations requiring legislation were included in the Youth Justice and Criminal Evidence Act 1999 and will enable the court to order one or more of a range of measures to assist the witness in court. These include:

- screens round the witness box to prevent the witness viewing the defendant;
- giving evidence by live TV link;
- assistance with communication;
- video-recorded evidence in chief;
- use of an intermediary;
- video-recorded pre-trial cross-examination;
- clearing the public gallery in sex offence cases and cases involving witness intimidation.

8.14 The 1999 Act also amends the law on competency. This provides that as a general rule, all people, whatever their age, are competent to act as witnesses unless they cannot understand questions asked of them in court or cannot answer them in a way that can be understood, with, if necessary the assistance of any of the special measures above. The legislation also makes clear that those who are competent to give evidence but who are not allowed to give evidence on oath may give evidence unsworn. The Government is aiming to implement the majority of the special measures in the Crown Court by Spring 2002.

Physical Interventions

8.15 Many organisations and individuals are concerned about the inappropriate use of physical interventions with adults and children with learning disabilities. The Department of Health will be issuing guidance clarifying policy on the appropriate use of physical interventions later in 2001.

People with learning disabilities in prison

8.16 Prisoners with learning disabilities present a wide range of issues. The Prison Service seeks to identify their individual needs for education and health care within the framework of addressing their sentence requirements. Prison establishments have to balance the resources needed to deliver this level of care with the many other demands of prisoner management.

Resources and Best Value

8.17 The Government's aim is to ensure that people with learning disabilities gain fair access to, and maximum benefit from, all available resources, whether in mainstream services or specialist provision for people with learning disabilities. In order to achieve this, decisions about resource allocation need to be evidence-based and take account of the likely increase in demand for services from people with learning disabilities.

8.18 We know that expenditure on and costs of services for people with learning disabilities vary significantly from one authority to another. The scale of these variations is difficult to justify, and we believe that there is scope for the money currently devoted to learning disability services to be used more effectively. The application of Best Value principles will achieve better value for money. Many councils have chosen learning disability as an area for Best Value Reviews. To be most effective, such reviews will need to look at services from a whole systems perspective, rather than considering particular services, such as day services in isolation. They should be person-centred in their approach. Advice on designing such reviews will be available in 2001.

WORKFORCE TRAINING AND PLANNING

Government Objective: To ensure that social and health care staff working with people with learning disabilities are appropriately skilled, trained and qualified; and to promote a better understanding of the needs of people with learning disabilities amongst the wider workforce

Problems and Challenges

8.19 Implementing the Government's proposals will require a new focus on the skills and training of the social care and health workforce. While the data are not reliable, there may be as many as 83,000 people in the learning disability workforce (33,000 in local councils, 30,000 in the voluntary and independent sectors, 20,000 in the NHS). The problems for national Government, local agencies and individuals are:

- An estimated 75% of staff are unqualified;
- Difficulties in recruitment and retention of professional and care staff;
- Low status among the workforce;
- Few recognised accredited training qualifications;
- Little attention to workforce planning;
- Variable involvement of service users and carers in training or planning.

8.20 We need to be confident that people in this field are equipped to work in the new ways required by the new strategy. The challenge is to ensure that in future people working or dealing with people with learning disabilities are:

- Better trained and qualified with a commitment to lifelong learning;
- Skilled at working in partnership with users and carers;
- Confident in working in multi-professional teams, and across agency boundaries;
- Culturally competent;
- Part of a local workforce and services which represent their communities;
- Well led and managed.

8.21 People with learning disabilities come into contact with a wide range of other professionals in their daily lives: staff in social security offices, the Employment Service and housing agencies; teachers and lecturers; police; GPs and other staff in the NHS. All these groups would benefit from a wider understanding of the needs of people with learning disabilities so as to overcome any lingering prejudice and enable people to make use of services on an equal basis with other citizens. This is demanding but must be more than window dressing if the provisions of the Disability Discrimination Act are to be met.

What More Needs To Be Done

KEY ACTIONS – WORKFORCE

- Health and Social Care Workforce Strategies to provide new opportunities for learning disability staff.
- Learning Disability Awards Framework introduced in April 2001.
- Learning Disability Development Fund to support range of leadership initiatives.
- Local Workforce Planning and Training Plans.

Health and Social Care Workforce Strategies

8.22 The Government has set in train major changes to lifelong learning and training. The Learning and Skills Council with its Local Learning Partnerships are expected to promote opportunities for education and lifelong learning, which will help develop a knowledge based approach in the workforce. The Department for Education and Employment's scheme to establish Individual Learning Accounts (ILAs) will help individuals meet the costs of training. The Government has set out general workforce strategies for health and social care which offer new opportunities for the learning disability field. The new Quality Framework for Social Care recognised the need for a new focus on workforce training and development. The NHS Plan promises all staff receiving dedicated vocational training – including those working in the learning disability field – a £150 individual learning account to 'top up' the contribution from the Department for Education and Employment scheme.

8.23 The Training Organisation Personal Social Services (TOPSS) National Training Strategy (endorsed by Government) contains specific proposals about learning disability. In 2001/2002 £2 million is being provided for TOPSS to support implementation of the Training Strategy. TOPSS will use the funds to roll out training based on the new Induction Standards for social care staff. TOPSS Regional Forums will administer this funding.

8.24 In each area the new NHS Workforce Confederations will involve all service providers- health, social care, independent and voluntary. TOPSS Regional Training Forums should work together with the Confederations to maximise the impact of training for staff in all sectors. The Confederations will have increased capacity to consider local workforce demands in learning disability. The Government will ensure that the work of each Confederation takes full account of the proposals set out here.

Learning Disability Awards Framework (LDAF)

8.25 The Government recognises that the levels of skills, training and qualification in the learning disability workforce need to be raised. We are therefore introducing from April 2001 a new Learning Disability Awards Framework, within the existing qualifications structures, to provide a recognised route to qualification and career progression for care workers in learning disability services. By April 2002 all new entrants to learning disability services will be registered for the new awards. The Framework is based on two new vocational qualifications:

- A level 2 Certificate in working with people with learning disabilities;
- A level 3 Advanced Certificate in working with people with learning disabilities.

Government Targets

From April 2002 all new entrants to learning disability care services should be registered for qualification on LDAF.

By 2005 50% of front line staff should have achieved at least NVQ level 2.

8.26 The new qualifications provide a comprehensive summary of learning outcomes, mapped against occupational standards. The new Framework will enable staff and employers to plan career paths and

In Bristol Social Services and Health we already provide a structured programme of training on issues such as ‘Protecting Vulnerable Adults’ and ‘Working with Challenging Behaviour’. LDAF is what we’ve been waiting for – a framework which will give staff a nationally recognised qualification for all the learning they have done. Because of the new Awards, staff will be motivated to think more about their own development, and there will be close links with the NVQ level 3, which will all help towards creating a better qualified workforce. This will benefit the people who use our services – which is really what the whole thing is about!

Bristol Social Services and Health

provide a route for people to progress to higher education and professional qualifications.

8.27 In partnership with TOPSS we have set some ambitious targets for rollout of the Framework. These will be monitored through data collected from the awarding bodies, National Open College Network and City and Guilds Affinity.

8.28 The next phase of the work on LDAF is in hand to bring levels 4 and 5 into the Framework. The General Social Care Council comes into operation in October 2001. The Department will explore with the Council how the Learning Disability Awards Framework can be linked to registration requirements for the learning disability sector.

Involving Users and Carers

"I want staff who treat you well, who know how to treat you properly"

8.29 The best way to achieve this is to promote the involvement of people with learning disabilities and their family carers in training and development activities. Staff and managers at all levels in organisations need to have an opportunity to hear directly from people with learning disabilities about their expectations. Some authorities have already begun to enable service users to play an effective role in the design and delivery of training to both managers and front-line staff.

Wendy's Job

Wendy has a job teaching health care staff. '*Teaching Doctors about Disability is very powerful and I enjoy it, but am exhausted afterwards. Getting the job in the first place was very difficult, I was lucky I had the right support, but it was really, really hard and I had to do a lot of preparation before I started!*'

Leadership

8.30 Effective leadership is essential for achieving the changes required. The Government will use the Learning Disability Development Fund to support a range of initiatives aimed at enhancing professional and managerial leadership in learning disability services. As part of the programme of work to implement this White Paper, we will also:

- Further develop the leadership capacity of people with learning disabilities and carers;
- Work in partnership with elected local councillors who have an important role to play in promoting positive acceptance of people with learning disabilities by the wider community;
- Recognise the valuable role to be played by academic leadership in creating and developing appropriate learning systems, stimulating investment in applied research and teaching and encouraging a new generation of leaders.

Local Workforce Plans

8.31 Learning Disability Partnership Boards will be required to develop a workforce and training plan. These should cover how service users and carers are being involved in training and workforce matters, the content and quality of health professional training, resourcing training and development needs across all organisations in the field including the independent sector and proposals for dealing with any shortfall in staffing.

People with Additional and Complex Needs

8.32 Good quality services will ensure that people with additional and complex needs are appropriately cared for so that their needs are well managed and they lead fulfilling lives. This includes people who:

- have severe and profound disabilities (including those with sensory impairments);
- have epilepsy;
- have an autistic spectrum disorder and also a learning disability;
- present with behaviour that challenges their carers and service providers;
- develop conditions associated with old age.

Margaret's Life

Margaret lived almost all her life in largish homes with people she didn't particularly enjoy being with. She acquired neither language nor formal signing, but was very well able to make her wishes known. She lost contact with her family once her mother died, but acquired a long-term personal advocate who gave her links with the outside world and helped her do some of the things she enjoyed: meals out, long walks, her own personal holiday. This was the one person who was "there for her", and the advocate was with her during her last days and when she died.

People with severe and profound disabilities

8.33 People with severe and profound learning disabilities often have other associated health problems such as physical disabilities, sensory impairments and epilepsy. They will almost always require a greater level of health care support than is usually available from a primary health care team. Members of the specialist learning disability service should provide additional support to the primary health care team to help them manage the complex health needs of those with multiple disabilities. In addition they may need access to a range of medical, nursing and other health services including physiotherapy, occupational therapy, speech and language therapy and orthopaedic services. Those who are technology dependent will require substantial additional support. The numbers of children who are technology dependent are relatively small, but an increasing number are surviving into adulthood.

8.34 People with profound and complex disabilities may have difficulty communicating their needs and wishes. They may need the support of someone who knows them well such as a family member, an advocate or a supporter. Nevertheless, it is important to enable people with profound and complex needs to exercise as much control as possible over their own lives.

People with epilepsy

8.35 The rate of 'active' epilepsy for people with mild or moderate learning disabilities is 5% compared to a normal rate of 0.5% in the general population. We may expect to find 30% of people with severe learning disabilities at risk of developing epilepsy, rising to 50% among those with profound learning disabilities. The condition originates in childhood for the majority. For people with Down's syndrome the onset of seizures in middle age may be associated with the onset of dementia.

8.36 Modern diagnostic investigations include referral to a specialist with expertise in epilepsy for detailed examination. People with severe and profound disabilities may have difficulties in co-operating with the investigations and specialist neurological clinics may be reluctant to accept such referrals. All people with learning disabilities are entitled to have access to specialist clinics, including tertiary services. Adequate and appropriate facilitation must be available to enable this to happen. Good support of the person with epilepsy involves careful and sympathetic understanding, effective monitoring of medication and support of daily routines to minimise the impact of factors that may provoke seizures.

People with learning disabilities and autistic spectrum disorders

8.37 Many people with severe and profound learning disabilities have autistic behaviours, even if not formally recognised. It is important that all services for people with learning disabilities have the skills to recognise and make adequate provision locally for them although the majority will not need autism specific services. The presence of an autistic disorder is normally first recognised in early childhood. The diagnosis depends on a full and competent assessment from a child and adolescent psychiatric, paediatric or learning disability service that specialises in this area. A number of new diagnostic instruments have recently been introduced and are currently being evaluated.

8.38 Many parents face lengthy waiting times for early diagnosis of autistic spectrum disorders. This often reflects the high workload of child development centres and Child and Adolescent Mental Health services and a lack of skilled expertise in diagnosing autistic spectrum disorders. This is in part being addressed by a joint initiative by the Department of Health and Royal College of Psychiatrists to develop a training programme for paediatricians with special expertise in mental health disorders.

8.39 The Department of Health has asked the Medical Research Council to obtain a clear and comprehensive picture of current knowledge about the incidence, prevalence and causes of autism and the strength of the evidence which underpins that knowledge. The Medical Research Council will submit a report to the Department of Health in autumn 2001. This will be circulated more widely to a range of policy-makers, patients, interest groups, the research community and the public.

8.40 Recent research suggests that family based early intervention for children with autistic spectrum disorders may result in improvements in skill and behaviour. Early intervention helps a significant number to overcome their disability sufficiently to attend mainstream schools. However, throughout their lives the majority of people with autistic spectrum disorders require educational, social, psychological and therapeutic interventions. Real choice is often limited by what is available rather than what might best suit the individual, and referral to residential services far from home is not uncommon. The Government will continue to work with the relevant professional bodies and other experts on autism to consider how screening, diagnosis and early intervention can be improved.

8.41 Although we focus on the needs of those individuals with autism who have learning disabilities, some general principles apply. Children with autism are children first and their needs as children should be the main focus. Whether or not they have learning disabilities in addition to their autism, they should therefore benefit from our proposals for improving services for disabled children.

8.42 Adults with autism need a range of living and working environments. Those who require intensive treatment and support are often unable to access local services and are referred to residential services far from home. While this may suit some individuals, others may prefer to live in their local community, take part in a local day service, find a job or seek supported employment. Person-centred planning should make it possible for individuals to be able to exercise their choice in how their housing and support is provided.

People with learning disabilities who have challenging behaviour

8.43 Commissioning and providing services for people who present significant challenges is one of the major issues facing learning disability services. The presence of challenging behaviour does not make an individual the responsibility of the NHS, although the NHS is responsible for commissioning and providing appropriate health input including intensive support from health professionals. The report of the Mansell Committee (Department of Health 1993) provided guidance on this and stressed that services should be commissioned on an individualised basis and should seek to promote inclusive lifestyles.

8.44 Challenging behaviours are best thought of as being a way in which people respond and try to gain control over difficult situations. Sometimes the challenging behaviour may be triggered by pain and a full medical assessment should always be undertaken. Psychotropic medication may be very effective when there is an underlying psychiatric disorder but there is concern that too often this medication is used as an alternative to adequate staffing. Modern behavioural approaches can result in significant short and medium term reductions in the severity of the behaviour. Learning Disability Partnership Boards should ensure that local services develop the competencies needed to provide treatment and support within the local area. To facilitate this, we have made developing specialist services for people with severe challenging behaviour and/or autism one of the priorities for the capital element of the Learning Disability Development Fund.

Older people with learning disabilities

8.45 Many people with learning disabilities now in their 50s and 60s were not expected to outlive their parents. Improved medical and social care now means they are living longer. Life expectancy is influenced by the severity of the learning disability. Those with severe and profound disabilities tend to die younger. As with the rest of the population women survive longer than men. Many of those now entering old age have spent most of their lives in long-stay hospitals and are likely to be adjusting to a new life in a home of their own, in supported living or in a small group home. A small number have continued to be in the care of the NHS in continuing care provision.

8.45 There are some people with learning disabilities over the age of 75, who have shown significant physical and mental deterioration with age, who have high dependency needs and who make considerable demands on health and social services. Their difficulties as older people overshadow any problems associated with their learning disability and their needs are practically identical to those of the elderly population as a whole. Person-centred plans for these individuals should be developed in the context of services for elderly people.

8.46 There are other older people with learning disabilities who are more mentally alert and have aspirations more typical of younger people. They may be misplaced in older peoples' homes living alongside much older and more incapacitated people. Plans for these individuals should be developed around packages of occupational and recreational activities and residential support which takes account both of their learning disabilities and the ageing process. They should be enabled to be as actively engaged as possible.

8.47 Those who develop Alzheimer's disease have very special needs. About a third of those with Down's syndrome may be expected to show clinical evidence of dementia, but others without Down's syndrome may also develop dementia. In Down's syndrome the onset of dementia may be from 35 years of age or earlier and their health often deteriorates quite rapidly. Providing good quality support for these individuals is a major challenge. The Government will expect learning disability services to work with the specialist mental health services to ensure that, between them, appropriate supports are provided for younger people with learning disabilities suffering from dementia.

8.48 The NSF for Older People will set out a framework that applies to services for all people over 65 years of age. But for people with learning disabilities the ageing process may begin much earlier. This means that planning for the needs of "older people" with learning disabilities may need to include a more extended population, perhaps taking account of those aged from 50 years upwards. Developing the person-centred approach to planning services described in Chapter 4 will enable local agencies to address the needs of older people with learning disabilities. Local Partnership Boards will ensure that there is co-ordination between learning disability services and older people's services so that people can access the services which are most appropriate to their needs.

PART THREE:

DELIVERING CHANGE

CHAPTER 9

PARTNERSHIP WORKING

Government Objective: To promote holistic services for people with learning disabilities through effective partnership working between all relevant local agencies in the commissioning and delivery of services.

9.1 This objective aims to promote:

- **Rights:** local Partnership Boards will need to ensure the availability of service options to meet people's assessed needs and wishes;
- **Independence:** agencies responsible for mainstream housing, education, employment and leisure will be fully included in local planning and commissioning;
- **Choice:** greater integration between agencies will open up wider service options for all people;
- **Inclusion:** people with learning disabilities and their families will be given the opportunity to be involved in local partnerships.

This objective is concerned with services for adults, with partnership for children services continuing to be addressed through Children Services Plans.

Problems and Challenges

9.2 Effective partnerships are key to achieving social inclusion for people with learning disabilities. Learning disability services have traditionally shown innovative approaches to partnership working. However, these are not widespread for reasons including:

- A lack of agreement about values and service objectives;
- An inability or unwillingness to agree on financial arrangements;
- Low priority being given to joint working within organisations.

9.3 In many places, people with learning disabilities and their families continue to be passed between organisations and professionals with insufficient clarity about where responsibility rests for ensuring effective service provision. Community learning disability teams were forerunners in partnership working, but they have not consolidated their position.

9.4 People with learning disabilities and their families need to have confidence that all organisations are working together to achieve integrated service planning and commissioning, and that they can gain access to their choice of services through one clear access route.

What More Needs To Be Done

KEY ACTIONS: PARTNERSHIP WORKING

- Learning Disability Partnership Boards to be established by October 2001.
- National support to partnership working to be provided through the Learning Disability Development Fund, Implementation Support Team and the production of good practice advice.
- Partnership Boards to agree plans for the use of Health Act flexibilities in the updated Joint Investment Plan (JIP).
- Further Department of Health guidance on partnership working and future role of community learning disability teams.

Partnership Boards

9.5 The Government intends to build on existing inter-agency planning structures to establish Learning Disability Partnership Boards in all local authority areas by October 2001. Partnership Boards will be responsible for those elements of the Government's proposals which relate to services for adults with learning disabilities. Services for disabled children will continue to be addressed through children services planning structures. The Partnership Board will operate within the overall framework provided by Local Strategic Partnerships (LSPs).

9.6 The development of Local Strategic Partnerships (LSPs) offers a framework for local partnership working, bringing together public, private, community and voluntary sectors in order to provide effective co-ordination. These arrangements aim to simplify and expand the scope of partnerships concerned with community well-being. Many areas already have a strategic partnership on which an LSP can build. Our proposals for partnership working in learning disability will fit within the overall umbrella offered by LSPs. Close links between Learning Disability Partnership Boards and LSPs will ensure a common direction and help to address wider issues, such as access to other local services, including transport.

9.7 Learning Disability Partnership Boards will not be statutory bodies. They will be responsible for:

- Developing and implementing the Joint Investment Plan for delivering the Government's objectives;
- Overseeing the inter-agency planning and commissioning of comprehensive, integrated and inclusive services that provide a genuine choice of service options to people in their local community;
- Ensuring that people are not denied their right to a local service because of a lack of competence or capacity amongst service providers;
- The use of Health Act flexibilities;
- Ensuring arrangements are in place to achieve a smooth transition to adult life for learning disabled young people.

9.8 Learning Disability Partnership Boards should particularly ensure that:

- people with learning disabilities and carers are able to make a real contribution to the Board's work;
- the cultural diversity of the local community is reflected in its membership;
- local independent providers and the voluntary sector are fully engaged.

9.9 It will be the responsibility of the chief executive of the local council to ensure that the Partnership Board is in place. Membership should include senior representatives from social services, health bodies (health authorities, Primary Care Trusts (PCTs)), education, housing, community development, leisure, independent providers, and the employment service. Representatives of people with learning disabilities and carers must be enabled to take part as full members. Minority ethnic representation will be important in view of the Government's commitment that their needs should not be overlooked.

9.10 The Learning Disability Development Fund and Implementation Support Team will make partnership development an early priority. The Department of Health will issue further guidance on partnership working in 2001.

Health Act Flexibilities

9.11 The new flexibilities introduced by the Health Act 1999 (see glossary) already provide opportunities to improve partnership working. They also provide the framework within which Learning Disability Partnership Boards will be required to operate. The NHS Plan makes clear that the Government expects the partnership flexibilities to be used in all parts of the country. Some localities are making early use of these flexibilities in the learning disability field, and we believe that wider use of these flexibilities will benefit people with learning disabilities and their families.

9.12 The Government expects all agencies involved in the Partnership Boards to show in their updated JIPs that they have fully considered how to use the Health Act flexibilities to underpin effective partnership working.

9.13 Joint Investment Plans will be evaluated and monitored to ensure effective partnership working. Evidence of failings in partnership arrangements will be taken into account in determining the allocation of the new Learning Disability Development Fund. Where there is evidence that services for people with learning disabilities are failing, partnership working is unsatisfactory and the Health Act flexibilities not being properly used, the Government will consider use of the new powers of intervention contained in the Health and Social Care Bill, which will enable the Department to direct the use of the partnership arrangements.

9.14 The Government places emphasis on the importance of promoting choice and achieving inclusion for people with learning disabilities through close partnership between health and social services and a wide range of other agencies including employment, education, housing and the and voluntary and independent sectors. In this context, it is likely that the leadership of the local partnership will rest with the local council, making use of one or more of lead commissioning, joint commissioning and pooled budgets.

Cumbria County Council, Morecambe Bay Health Authority, and North Cumbria Health Authority have agreed to commit £20 million to a pooled fund for learning disabilities. The intention is to enable an integrated strategy to be delivered, providing a consistent and high quality service, which can respond to the needs of individuals. The Partnership Arrangement has been established on the basis of broad participation from users, carers, providers – statutory and independent. It has clear performance measures based on priorities identified through the consultation process – including improving respite care, day care and activities, and reducing the size of accommodation units. Lack of co-terminosity has not been a barrier to development. A project manager has been appointed who is focusing on where integrated provision would enable the strategy to be fulfilled.

9.15 However, where effective partnerships are not established with local council leadership, the Government will consider using its intervention powers to require the development of a Care Trust. There may also be particular local circumstances which make the creation of a Care Trust an appropriate way to achieve local integration of services.

The Role of Primary Care Trusts (PCTs)

9.16 Primary Care Trusts (PCTs) will be key players in the Learning Disability Partnership Boards. As PCTs become more firmly established and develop their commissioning responsibilities, they will be the lead health body for learning disability services. They will need to develop skills and knowledge in commissioning learning disability health services. Partnership Boards will not constrain the freedom of emerging PCTs, but will enable them to enhance the effectiveness of their overall contribution to improving health outcomes for people with learning disabilities.

Integrated Professional Working

9.17 Professional structures need to ensure that people with learning disabilities and their families have easy access to services from all agencies. To achieve this, Partnership Boards should review the role and function of community learning disability teams in order to ensure that:

- All professional staff become accountable for the outcome of their work to the local partnership arrangements – whilst ensuring the retention of appropriate professional accountabilities and support;
- All professional staff become a resource for the local implementation of the White Paper and to help achieve social inclusion for people with learning disabilities;
- Organisational structures encourage and promote inclusive working with staff from the fields of housing, education, primary care, employment and leisure.

9.18 The Department of Health guidance on partnership working will provide further advice on the future role of community teams.

CHAPTER 10

MAKING CHANGE HAPPEN

10.1 Delivering the Government's ambitious plans for people with learning disabilities will take time, as real change always does. Improving the lives of people with learning disabilities is a complex process which requires a fundamental shift in attitude on the part of a range of public services and the wider local community. This will not be easy. It needs real leadership at both national and local levels, supported by a long-term implementation programme with dedicated resources and on-going action to monitor delivery. This chapter sets out how the Government intends to approach this challenging task.

10.2 The Department of Health in partnership with the Department for Education and Employment, the Department of the Environment, Transport and the Regions and the Department of Social Security will issue further guidance on what is expected of local agencies in order to implement the new strategy.

National Action

Learning Disability Task Force

10.3 The Government will set up a national Learning Disability Task Force to take forward the implementation. The role of the Task Force will be to monitor and support implementation by acting as a champion for change and improvement at local level. Drawing on the knowledge and experience of members, the Task Force will also offer advice to Government on the continuing development of learning disability policy. It will focus on the adult elements of the Government's proposals, and its membership will be drawn from a wide range of interests, including minority ethnic communities. The Children's Task Force will continue to have the lead on disabled children's issues and we will ensure that effective links are in place between the two.

10.4 People with learning disabilities and carers will be full members of the Task Force. We will ensure that effective links are in place between the Task Force and the National Forum for People with Learning Disabilities.

Learning Disability Development Fund

10.5 To support implementation of the new proposals for adults, the Government will create a new Learning Disability Development Fund of up to £50 million per annum, of which up to £30 million will be revenue funding and £20 million capital. This will be introduced in April 2002 and will be targeted on the Government's priorities.

10.6 The revenue element of the Development Fund will be created from that element of the current old long-stay adjustment within general health allocations which is released as former long-stay patients die. We will conduct a census of old long-stay patients through the NHS regional offices later in 2001 in order to determine the final size of the Development Fund. We will announce this in good time before April 2002.

10.7 The Development Fund will be used to support our priorities for service change. Priorities for the use of revenue funding will be:

- Modernising day centres;
- Completing the reprovision of the remaining long-stay hospitals to enable people to move to more appropriate accommodation by April 2004;
- Developing supported living approaches for people with learning disabilities living with older carers;
- Promoting the further development of advocacy;
- Supporting the wider introduction of person-centred planning;
- Enhancing leadership in learning disability services.

10.8 Priorities for the use of the capital will be:

- enabling local providers to develop specialist services for people with severe challenging behaviour;
- developing integrated health and social services facilities for children and young people with severe disabilities and complex needs;
- developing supported living approaches for people with learning disabilities living with older carers.

10.9 Learning Disability Partnership Boards will be required to submit updated Joint Investment Plans (JlPs) to the Department of Health by January 2002, setting out their plans for implementing the White Paper. Updated JIPs should include bids against the capital element of the Learning Disability Development Fund. Decisions about the allocation of the Learning Disability Development Fund will require the social care and health regions of the Department of Health to be satisfied that the JlPs are acceptable and that in particular they provide evidence of satisfactory partnership arrangements.

10.10 The Learning Disability Development Fund will be made available subject to the condition that the resources may only be used where they are deployed as part of pooled funds under the Health Act flexibilities. This will enable the Learning Disability Development Fund to support the implementation of all aspects of *Valuing People*. Learning Disability Partnership Boards will be required to show how they will make use of the Health Act flexibilities to enhance partnership working and this will be taken into account in decisions about the allocation of the Development Fund.

Implementation Support Team

10.11 We believe that a strong national lead which provides effective support to local action will be vital in delivering the vision set out in *Valuing People*. The Government will therefore set up a national Implementation Support Team during 2001. The team will be led by a Director with a Development Worker based in each of the eight Department of Health regions and will be charged with promoting good practice and sharing practical experience across the country.

Implementation Support Fund

10.12 The Government will set up an Implementation Support Fund of £2.3 million a year for 3 years from April 2001 to provide central support for key aspects of the new strategy. (This includes £300,000 for increasing volunteering opportunities for citizen advocates.) Priorities for the Fund include:

- Development and expansion of advocacy services;
- Establishment of a National Learning Disability Information Centre and Helpline in partnership with Mencap;

- Funding a number of development projects on key priorities, including person-centred planning, partnership working and a scoping study of the interface between employment and day services;
- Extension of the Learning Disability Awards Framework.

Improving the Information Base

10.13 National data on learning disability issues are currently underdeveloped. The Government intends to take steps to improve the situation. During 2001/02, the Department of Health will commission a national survey of people with learning disabilities in contact with social services in order to improve our knowledge and provide a stronger baseline against which to evaluate the impact of *Valuing People*.

10.14 The Department of Health will also be undertaking a project to improve its own data collection in the learning disability field by establishing which activities and services should be the subject of regular statistical returns. For disabled children, the children in need census is already improving the knowledge base, and the forthcoming Integrated Children's System will set out the minimum data requirements for collecting information about individual children and families, including disabled children.

Research

10.15 Research has an important role to play. Findings from research contribute towards fostering an evidence based approach to service delivery. The Department of Health will be funding a £2 million research initiative *People with Learning Disabilities: Services, Inclusion and Partnerships* starting in 2001/02 and lasting for four years. The areas we wish to study are:

- Service delivery in health and social care and its effectiveness to identify elements of good practice, implementation and sustainability;
- Social inclusion, including access to good health care, and the factors which create disability barriers in people's lives;
- Organisation development to show how staff performance in learning disability services can be supported to achieve better services.

10.16 The aim of this initiative is to generate a knowledge base to inform the implementation of our proposals. We expect to fund 6–10 studies. The initiative will be overseen by a reference group and its findings disseminated to complement the *Valuing People* implementation programme.

10.17 There is already a considerable amount of research activity on learning disability in the NHS. Over 130 separate research projects, as listed on the National Research Register (NRR), have recently been completed. About £3 million is being spent on 50 current studies. Topics being researched include the health needs of people with learning disabilities in the community. Among those recently completed were a study of women with learning difficulties and their experiences of cervical smear tests and research on the impact of training for carers, on the mental health of people with learning disabilities.

10.18 The NHS Information Authority will develop a National Electronic Library for Learning Disability. In 2001/2002 the Authority will be putting more resources into the pilot project.

Inspection

10.19 We shall ensure that the Social Services Inspectorate (SSI) and the Commission for Health Improvement (CHI) give attention to learning disability services within their national work programmes. During 2001/02, there will be a national inspection by SSI of learning disability services in order to assess how well placed local councils will be to implement the new strategy. Findings from the inspection will be used to inform the work and priorities of the Implementation Support Team.

Local Action

10.20 Learning Disability Partnership Boards will be accountable for implementing the proposals in *Valuing People* at local level. Boards will be expected to appoint a senior officer who will have lead responsibility for taking this forward.

10.21 Health and local authorities have already been asked to have learning disability Joint Investment Plans (JIPs) in place by April 2001. Guidance on the development of the learning disability JIP foreshadowed some of the key themes in the new strategy. The Government has therefore decided to build on the JIPs as the basis for local implementation of its proposals. Learning Disability

Partnership Boards will be required to develop local action plans as supplements to the JIP and to submit the updated JIP to the regional offices of the Department of Health by 31 January 2002. The JIPs will then be jointly evaluated by Department of Health social care and NHS regional offices.

10.22 As part of overall guidance on implementation, the Department of Health will issue guidance on the contents of the updated Joint Investment Plan (JIP). It will be essential that the JIP is agreed by all agencies represented on the Learning Disability Partnership Board. The Government will expect people with learning disabilities, carers and the local voluntary and independent sectors to be fully involved in this process.

Delivery Plan

10.23 Set out below are the key actions which will be taken by the Government and by local agencies to implement the new strategy. This needs to be at least a five year implementation programme. Although we are clearer now about the early milestones, the Learning Disability Task Force will revisit this plan on a regular basis to roll it forward for future years.

Spring 2001

- Recruitment of Implementation Support Team begins
- Funding for Citizen Advocacy Network and Self-Advocacy work comes on stream
- Work begins in partnership with Mencap to develop National Information Centre
- Regional office census of former old long-stay patients carried out
- Guidance on person-centred planning commissioned
- Guidance on Physical Interventions issued
- All new entrants to learning disability care services should be registered on LDAF

Summer 2001

- Learning Disability Task Force established
- Issue guidance on implementation
- Issue joint DH/DETR guidance on housing for people with learning disabilities
- DH/DfEE study into interface between day services and supported employment commissioned and DH/DfEE joint working group set up
- Work under way to establish National Learning Disability Users Forum

Autumn 2001

- Implementation Support Team up and running
- Guidance on direct payments issued
- Good practice materials on learning disabled people and decision making issued
- Good practice materials on partnership issued
- Learning Disability Partnership Boards in place
- Issue guidance on person-centred planning

Winter 2001/02

- Learning Disability Partnership Boards submit updated JIP to the Department of Health which is to act as local action plan
- Complete analysis of JIPs and notify decisions about Learning Disability Development Fund

Spring 2002

- Introduction of new Learning Disability Development Fund
- Agree local framework for person-centred planning and begin implementation
- Inter-agency framework for quality assurance to be agreed
- Plans for closing remaining long-stay hospital units agreed

Winter 2002/03

- Day service modernisation programme agreed
- JIP updated
- Agree Housing Strategy
- Agree Employment Strategy

Summer 2003

- All Learning Disability Partnership Boards to have agreed framework for Health Action Plans
- Health facilitators identified.

Winter 2003

- Person-centred planning for people in long-stay hospitals completed.
- Full range of employment and support service options in place

Targets post March 2004

- Programme to enable people still living in long-stay hospitals to move into more appropriate accommodation by April 2004
- 50% of front line staff to have achieved at least NVQ level 2 – 2005
- All people with a learning disability to be in receipt of a HAP by June 2005
- Modernisation of day centres completed by 2006

Monitoring Delivery

10.24 Delivering the changes set out in *Valuing People* involves a complex range of agencies, including at least four Government departments and a wide range of local agencies. The large number of stakeholders involved makes it particularly important that the Government takes a comprehensive approach to monitoring implementation. We will ensure that existing performance assessment mechanisms across health, social services, education, employment and housing enable us to monitor implementation of the key initiatives. Best Value and the performance assessment arrangements for social services are likely to make a particularly important contribution, given the lead role that local councils have in taking forward our proposals.

10.25 We have reviewed the existing data and performance indicators which are already in place on learning disability services, and are proposing new performance indicators for use as part of the further development of JIPs. These are set out at Annex A in support of the Government's objectives for learning disability services. We intend to replace the existing national performance indicators within the social services Performance Assessment Framework with new outcome-focused indicators. We shall consult Local Government Association, Association of Directors of Social Services and the NHS Confederation on more detailed proposals.

Conclusion

10.26 We do not underestimate the difficulties involved in delivering our ambitious new vision for people with learning disabilities. The principles of rights, independence, choice and inclusion we put forward are challenging and have far reaching implications for all those agencies – public, independent and voluntary – who work with people with learning disabilities. Enabling people with learning disabilities to have their voices heard and have wider opportunities for a fulfilling life as part of the local community is central to our message. Delivering this involves new ways of working in more effective partnerships. But getting it right for people with learning disabilities will show what can be achieved with and for one of the most vulnerable and socially excluded groups in our society.

ANNEXES

ANNEX A

OBJECTIVES AND SUB-OBJECTIVES, TARGETS AND PERFORMANCE INDICATORS

Objective 1: Disabled children and young people

To ensure that disabled children gain maximum life chance benefits from educational opportunities, health care and social care, while living with their families or other appropriate settings in the community where their assessed needs are adequately met and reviewed.

BY:

Sub-objective 1.1

Ensuring early identification of disabled children to enable them to access appropriate and timely intervention and support

Sub-objective 1.2

Ensuring that parents and disabled children receive reliable, comprehensive and culturally appropriate information about services on a multi-agency basis from the statutory and voluntary sectors.

Sub-objective 1.3

Increasing the number of disabled children in receipt of a range of family support services and the number of hours provided.

Sub-objective 1.4

Maximising the number of children with disabilities/special educational needs who receive good quality co-ordinated care and education in inclusive settings in their own communities.

Sub-objective 1.5

Ensuring that disabled children receive appropriate health care throughout childhood so as to enable them to participate fully in education, family and community life.

Sub-objective 1.6

Increasing the number of disabled children who use inclusive play, leisure and cultural services including holiday play schemes, after schools clubs and pre-school provision with appropriate support if necessary.

Performance against this objective and associated sub-objectives will be measured through the Quality Protects programme

The above sub-objectives build on existing Government Objectives for Children's Social Services and will be finalised in the autumn Quality Protects circular

Objective 2: Transition into adult life

As young people with learning disabilities move into adulthood, to ensure continuity of care and support for the young person and their family, and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training or employment.

BY:

Sub-objective 2.1

Ensuring that each Connexions partnership provides a full service to learning disabled young people by identifying them, deploying sufficient staff with the right competencies and co-ordinating the delivery of appropriate supports and opportunities.

The Connexions Unit headline target for young people at risk (including people with learning disabilities) is: participation and achievement over time to converge with those in the population in the same age group

Sub-objective 2.2

Ensuring effective links are in place within and between children's and adult's services in both health and social services.

Objective 3: More choice and control

To enable people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person-centred approach to planning the services they need.

BY:

Sub-objective 3.1

Promoting the rights of people with learning disabilities

Sub-objective 3.2

Enabling advocacy to be available for people with learning disabilities who want or need it.

Proposed Performance Indicator and PAF Indicator: The amount spent by each council on advocacy expressed as the amount per head of people with learning disabilities known to the council

Sub-objective 3.3

Making direct payments available to all those people with learning disabilities who request them and who meet the requirements of the scheme.

Proposed Performance Indicator: % of people with learning disabilities receiving community based services who are receiving direct payments

Sub-objective 3.4

Developing locally agreed protocols and procedures to ensure services are based upon a person-centred approach.

Sub-objective 3.5

Ensuring that people with learning disabilities are fully and actively involved in all decisions affecting their lives.

Objective 4: Supporting carers

To increase the help and support carers receive from all local agencies in order to fulfil their family and caring roles effectively.

BY:

Sub-objective 4.1

Assessing the needs of carers and putting in place the services required.

Proposed Performance Indicator: % of adults with learning disabilities receiving community based services who are receiving short term breaks

Sub-objective 4.2

Establishing a complete picture of the number of older carers (ie those aged 70 and over) in the local area in order to plan services in partnership with them.

Proposed Performance Indicator: % of carers aged 70 or over for whom a plan has been agreed

Sub-objective 4.3

Providing services and support that meet the needs of carers from minority ethnic communities.

Sub-objective 4.4

Making sure that all agencies work in partnership with carers, recognising that carers themselves have needs which must be considered.

Objective 5: Good health

To enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary.

BY:

Sub-objective 5.1

Reducing the health inequalities experienced by people with learning disabilities.

Sub-objective 5.2

Enabling mainstream NHS services, with support from specialist learning disability staff, to meet the general and specialist health needs of people with learning disabilities.

Sub-objective 5.3

Promoting the development of NHS specialised learning disability services which are evidence based and delivered with a focus on the whole person.

The Department of Health will develop performance indicators to compare the health status of people with learning disabilities with that of the general population and will consult on these.

Objective 6: Housing

To enable people with learning disabilities and their families to have greater choice and control over where, and how, they live.

BY:

Sub-objective 6.1

Increasing the range and choice of housing open to people with learning disabilities in order to enable them to live as independently as possible.

PAF PERFORMANCE INDICATOR: B14 Unit Cost of residential and nursing care for adults with learning disabilities

Sub-objective 6.2

Ensuring people with learning disabilities and their families obtain advice and information about housing from the appropriate authorities.

Sub-objective 6.3

Enabling all people currently in NHS long-stay hospitals to move into more appropriate accommodation and reviewing the quality of outcomes for people living in NHS residential campuses.

Target: Enabling the people currently living in NHS long-stay hospitals to move to more appropriate accommodation by April 2004

Objective 7: Fulfilling lives

To enable people with learning disabilities to lead full and purposeful lives within their community and to develop a range of friendships, activities and relationships.

BY:

Sub-objective 7.1

Modernising day services to enable people to exercise real choice over how they spend their days

Proposed Performance Indicators:

- **Gross expenditure on day care as a percentage of expenditure on all non-residential services**
- **Ratio of expenditure on day and domiciliary services for people with learning disabilities to expenditure on residential provision for people with learning disabilities**

Sub-objective 7.2

Enabling people with learning disabilities to have access to a wide range of opportunities for education and lifelong learning in order to promote greater independence and maximise employment opportunities.

The Learning Skills Council (LSC) will set targets as part of its equal opportunities strategy

Sub-objective 7.3

Enabling people with learning disabilities to make full use of transport and access mainstream community and leisure services.

Sub-objective 7.4

Supporting parents with learning disabilities in order to help them, wherever possible, ensure their children gain maximum life chance benefits.

Sub-Objective 7.5

Making sure that people with learning disabilities receive the social security benefits to which they are entitled.

Objective 8: Moving into employment

To enable more people with learning disabilities to participate in all forms of employment, wherever possible in paid work and to make a valued contribution to the world of work.

BY:

Sub-objective 8.1

Ensuring that more people with learning disabilities find appropriate employment, including supported employment, which makes the most of their talents and potential.

Proposed National Target: Increase the employment rate of people with learning disabilities and reduce the difference between their employment rates and the overall employment rate of disabled people

Proposed Performance Indicator: number of people with learning disabilities in work as a proportion of those with learning disabilities known to the council

Sub-objective 8.2

Making sure that people with learning disabilities are actively helped to access employment related advice and guidance through mainstream and specialist advisory services.

Sub-objective 8.3

Ensuring that public services provide a lead in the employment of people with learning disabilities.

Objective 9: Quality

To ensure that all agencies commission and provide high quality, evidence based, and continuously improving services which promote both good outcomes and best value.

BY:

Sub-objective 9.1

Demonstrating that people with learning disabilities and their families are increasingly satisfied with services provided.

Sub-objective 9.2

Ensuring that the needs of people with learning disabilities from minority ethnic communities are recognised and addressed through the provision of appropriate services.

Proposed Performance Indicator: the proportion of people with learning disabilities from minority ethnic communities who are receiving services divided by the proportion of all people in the local population from minority ethnic communities

Sub-objective 9.3

Ensuring that local quality assurance frameworks for social care and health meet the needs of people with learning disabilities.

Sub-objective 9.4

Ensuring people with learning disabilities receive best value from publicly funded services.

Proposed Performance Indicator: Number of people with learning disabilities known to the local council per head of general population

Sub-objective 9.5

Ensuring that local adult protection policies and procedures (including those for protecting vulnerable victims and witnesses of crime) are in place and fully complied with.

Objective 10: Workforce and planning

To ensure that social and health care staff working with people with learning disabilities are appropriately skilled, trained and qualified; and to promote a better understanding of the needs of people with learning disabilities amongst the wider workforce.

BY:

Sub-objective 10.1

Introducing the new national framework for training, competencies, qualifications and skill levels in the learning disability workforce.

Targets

- **From 2002 all new entrants to learning disability care services to be registered with Learning Disability Awards Framework**
- **By 2005 50% of front line staff to have achieved at least NVQ Level 2**

- **Proposed Performance Indicator: Percentage of staff working in learning disability services achieving at least NVQ Level 2**

Sub-objective 10.2

Promoting awareness among the wider workforce (in areas such as housing, the wider NHS, transport and the Department of Social Security) of the skills, attitudes and knowledge needed to work with people with learning disabilities in a positive and respectful manner.

Sub-objective 10.3

Ensuring that local workforce plans are developed.

Objective 11: Partnership working

To promote holistic services for people with learning disabilities through effective partnership working between all relevant local agencies in the commissioning and delivery of services.

BY:

Sub-objective 11.1

Establishing local Learning Disability Partnership Boards to take responsibility for local delivery of the White Paper, led by the local council and with the active participation of all key stakeholders.

Target Date: October 2001

Sub-Objective 11.2

Making effective use of the Health Act flexibilities.

Sub-objective 11.3

Promoting effective partnership working by staff from all relevant disciplines and agencies.

The Department of Health will be consulting further with the Local Government Association, the Association of Directors of Social Services and the NHS Confederation on the proposed indicators and consequential changes to the PAF Indicators. The agreed set of indicators will then be used to assess performance in the supplements to JIPs required by January 2002.

The Department of Health will be commissioning a national survey of people with learning disabilities in order to improve knowledge about the lives of people with learning disabilities and their families. It is anticipated that fieldwork would begin towards the end of 2001/2002.

ANNEX B

GLOSSARY

Childcare Development Partnerships – *aim is to establish good quality affordable childcare in all communities. From 2001 all will be required to identify and train a special educational needs (SEN) co-ordinator.*

Children's Fund – *£450 million Government programme targeted at preventive work with vulnerable children (primarily in the 6 to 13 age group). Strong emphasis on voluntary sector delivery.*

Connexions Service – *brings together into a single strategy across Government policies for young people aged between 13 and 19. Provides advice and support, gives particular attention to those at greatest risk of not making a successful transition to further leering and adulthood.*

Direct payments – *cash payments service users can receive from social services departments to purchase for themselves services to meet their assessed needs. The only service they cannot be used for is permanent residential care.*

Disability Rights Commission – *set up following recommendations from the Disability Rights Task Force and the Disability Rights Commission Act 1999 to work towards the elimination of discrimination against disabled people. Came into operation April 2000.*

Health Act flexibilities – *provisions in the Health Act 1999 enabling local authorities to work more closely with health authorities to provide improved services.*

Intentional community – *services operated by independent sector organisation comprising houses and some shared facilities on one or more sites and based on philosophical or religious belief.*

Joint Investment Plans (JIPs) – *plans produced jointly by local authorities, health authorities, and other local stakeholders for the integrated provision of services for a range of client groups.*

Learning and Skills Council – *set up under the Learning and Skill Act 2000. Has overall responsibility for post-16 education below higher education.*

Learning Disability Advisory Group – *set up in 1998 to advise Ministers on issues affecting people with a learning disability. Members include professionals, NHS and LA representatives, voluntary organisations, researchers, service users, and parents.*

NHS residential campus – *service operated by an NHS Trust comprising housing, some of which will be clustered on one site, together with some shared central facilities and developed as a direct result of the closure of NHS hospitals.*

NHS Plan – *contains proposals for ensuring that health services more fully meet the needs of patients.*

Old long-stay patients – *patients with a learning disability who were admitted to hospital prior to 1 January 1970 and who were still receiving care on 1 April 1996.*

Quality Protects – *Government programme designed to improve children's social services.*

Reprovisioning – *developing alternative settings for services currently or formerly provided in long-stay hospitals, large hostels, day centres etc.*

Sure Start – *Government programme aimed at promoting the physical, intellectual, and social well-being of pre-school children.*

Village communities – *service operated by independent sector organisation comprising houses clustered on one site together with some shared central facilities.*

ANNEX C

BIBLIOGRAPHY

This lists some of the main publications which informed the development of *Valuing People*.

Abott, David: Morris Jenny, and Ward, Linda, (2000) *Disabled Children and Residential Schools; a Study of Local Authority Policy and Practice* Norah Fry Centre

Ahmad, Waqar, (2001) Centre for Research in Primary Care, University of Leeds, *Learning Difficulties and Ethnicity*

Association for Residential Care (1999–2000) *Training Networks Research*

Brown, Hilary, (2000) *Abuse and protection issues*, Centre for Applied Social and Psychological Development, Canterbury Christ Church University College

Chamba, Rampaul, et al, (1999) *On the Edge: Minority Ethnic Families Caring for a Severely Disabled Child*, Policy Press

Department for Education and Employment (1998), *Meeting Special Educational Needs: A Programme for Action*

Department for Education and Employment (2000), *Connexions: the Best Start in Life for Every Young Person*

Department of Health (1992) (Chairman: Prof. J L Mansell) *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs.*

Department of Health (Circular HSG (92) 42) Health Services for People with Learning Disabilities (Mental Handicap)

Department of Heath (Circular LAC (92) 15) *Social Care for Adults with Learning Disabilities* (Mental Handicap)

Department of Health, (1997) *People Like Us: The Report of the Review of the Safeguards for Children Living Away from Home*

Department of Health (1998) *Moving into the Mainstream: The Report of a National Inspection of Services for Adults with Learning Disabilities*

Department of Health (1998), *Signposts for Success in Commissioning and Providing Health Services for People with Learning Disabilities*

Department of Health (1998) *Disabled Children; Directions for their Future Care*

Department of Health (1999) *Once a Day*

Department of Health (1999) *Facing the Facts: Services for People with Learning Disabilities: Policy Impact Study of Social Care and Health Services*

Department of Health, (2000) *A Jigsaw of Services: Inspection of services to support disabled adults in their parenting role*

Department of Health, Department for Education and Employment, Home Office (2000) *Framework for the Assessment of Children in Need and their Families*

Department for Education and Employment, National Training Organisation (1997) *Learning and Working Together*

Emerson, Eric, (2000) *Challenging Behaviour: Analysis and Intervention in Intellectual Disabilities*, Cambridge University Press

Glendinning, Caroline, and Kirk, Sue,(1999) *The Community-Based Care of Technology Dependent Children in the UK: Definitions, numbers and costs*, National Primary Care research and Development Centre, University of Manchester

Gordon, David, Parker, Roy, Loughran, Frank, (2000) *Disabled Children in Britain, a re-analysis of the OPCS Disability Surveys*, the Stationery Office

Hester Adrian Research Centre, University of Manchester (1999), *Quality and Costs of Residential Supports for People with Learning Disabilities – Summary and Implications*

Local Government Management Board: (1999) *Recruitment Trends* (1999) *Recruitment & Qualifying WF* (1998) *SSD Qualifying WF/WF* (1997) *Human Resources for Personal Social Services*

Mencap (2000) *Learning Disability Strategy Initial Submission*

Mencap, (2000) *New targets for a new century: learning disability strategy*

Morris, Jenny, (1999) *Hurtling into the Void*, Pavilion Publishing,

Morris, Jenny, (1998) *Still Missing? The experiences of disabled young people living away from their families*, The Who Cares? Trust

NHS Cancer Screening Programmes (2000) *Good Practice in Breast and Cervical Screening for Women with Learning Disabilities*

NHS Executive (2001), *From Words Into Action: The London Strategic Framework for Learning Disability Services*

O'Bryan, Anne, Simons, Ken, Beyer, Steve, Grove, Bob, (2000) *A Framework for Supported Employment*, Joseph Rowntree Foundation

Russell, Philippa, (1998) Council for Disabled Children *Having a Say! Disabled Children and Effective Partnership in Decision Making*

Saving Lives: Our Healthier Nation. The Stationery Office (ISBN 0-10-143862-1)

Ward, Cally, *(2001) Family Matters, Counting Families In:* The report from the Family Carers working group

The six working groups listed in Annex D considered papers prepared by their members on a range of subjects.

ANNEX D

ADVISORY GROUPS AND WORKING GROUPS

Learning Disability Advisory Group

Ann Gross, Disability Branch, Department of Health (Chair)

Colin Beacock – Royal College of Nursing
Norma Brier – Norwood Ravenswood
Maurice Brook – Rescare
James Churchill – Association for Residential Care
Jean Collins – Values into Action
Yvonne Cox – NHS Confederation
Ian Davey – Association of Directors of Social Services
Eric Emerson – Institute for Health Research (Lancaster University)
Rob Greig – Community Care Development Centre
John Harris – British Institute of Learning Disabilities
Fred Heddell – Mencap
Sheila Hollins – St George's Hospital Medical School
Mary Lindsey – Royal College of Psychiatrists
Joan Maughan* – National Development Team
Bill Robbins – Association of Directors of Social Services
Noel Towe – Local Government Association
Jan Webb – Success in Shared Care
Chris Wells – Department for Education and Employment

* replaced Simon Whitehead

Department of Health officials:
  Catherine Baines – Disability Branch
  Alistair Brechin – Disability Branch
  Sue Carmichael – Nursing Division
  Elaine Cooper – Disability Branch
  David Ellis – Inspector, Disability Branch
  Patricia Parris – Disability Branch
  Oliver Russell – Senior Policy Adviser (Medical), Disability Branch

Services Users Advisory Group*

Change:
Paul Adeline
Mary Byrne
Andrew Gayle
Justine March
Jean Sapsford
Richard West

Mencap:
John Atkinson (died February 2001)
James Calvert
Mabel Cooper
Jenny Green
Margaret Perks

People First:
Michael Brookstein
Michelle Chinery
Andrew Lee
Carol Lee
Raymond Johnston
John Watson

Speaking Up Cambridge
Eve Rank-Petruzziello

Supporters
Tim Gunning
John Herzov
Andrew Holman
Penny Mendonca

* Representatives from the Service Users Advisory Group are also full members of the Learning Disability Advisory Group

Working Groups

Children

Catherine Baines – Department of Health (Joint Chair)
Peter Smith – Department of Health (Joint Chair)
Shobha Asar-Paul – Birmingham Social Services Department
Gillian Batt – Department of Health
Jayne Boyfield – Department of Health
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Richard Carter – Department of Health
Susan Clarke* – Department for Education and Employment
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Philippa Russell – Council for Disabled Children
Kim Sibley – Department for Education and Employment
Linda Ward – Rowntree Foundation

*replaced Kim Sibley

Carers

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Cathy Baines – Department of Health
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Ruth Bayard – Norwood Ravenswood
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Maurice Brook – Rescare
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Richard Kramer – Mencap
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Joan Maughan – National Development Team
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Health

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*replaced Jacqui Howard

Supporting Independence

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Michelle Chinnery – People First
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Gwylfa Evans – Association of Directors of Social Services
Jacqui Howard-Department of Health
Carol Lee – People First
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Frances Walker – Department of the Environment Transport and the Regions
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*replaced Jacqui Howard and Hester Ormiston

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Sue Carmichael – Department of Health (Joint Chair)
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Sally Burton – Department of Health
James Churchill- Association for Residential Care
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Debbie Mellor – Department of Health
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Building Partnerships

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Carole Bell – Department of Health
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James Churchill – Association for Residential Care
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Developing better services: modernising hospitals and reforming structures

Item Type	Report
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Developing Better Services

Developing Better Services

Modernising Hospitals and Reforming Structures

Department of Health, Social Services and Public Safety
An Roinn Sláinte, Seirbhísí Sóisialta agus Sábháilteachta Poiblí

June 2002

N.I.

Developing Better Services

Modernising Hospitals and Reforming Structures

Department of Health, Social Services and Public Safety
An Roinn Sláinte, Seirbhsísí Sóisialta agus Sábháilteachta Poiblí

June 2002

MINISTER'S FOREWORD

I commissioned a review of acute hospital services in August 2000, and asked the review group to make recommendations on the future profile of hospital services, taking account of issues of accessibility, safety, clinical standards and quality of services.

The review was set up against a background of many years of under-funding of health services, which has undermined and weakened their capacity to deliver the quality of service demanded of a modern hospital system. My objective was to develop an agenda for a major, and long overdue, modernisation of the acute hospital system.

The Executive has recognised the need to boost health and social care expenditure and has invested an additional £523 million in healthcare since the establishment of the Assembly. Of this, 80% has been required merely to maintain existing services.

While this additional and much needed expenditure is welcome, extra spending alone is not the answer. To provide a modern hospital system that will meet the needs of all our people, well into the future, will require a fundamental change in the way services are delivered and administered. Otherwise we will see services continue to decline and fall behind standards elsewhere.

In this paper I am setting out how I consider our hospital services need to be modernised and the decisions required to take these changes forward. My proposals are not about reducing acute services. Rather they aim to build upon the firm foundations of current services, to ensure that everyone will have prompt access to high quality acute care, delivered close to their homes wherever possible.

I would expect my proposals to bring about a new, modern and more effective hospital service, a service that is set up and resourced to meet the needs of the expected numbers of patients that it serves; deliver a world-class service with much improved outcomes, in areas such as cancer and heart disease; eliminate the problem of people waiting for admission and delayed discharges; meet peak demands without postponing normal activity; and substantially reduce waiting times, bringing them down to a maximum of three months for non-urgent cases, with priority cases treated much sooner.

Delivering quality care also demands organisational structures that are fit for purpose and equal to the challenges facing a modern health service. The need for organisational reform has been evident for some time, but the issues are complex. Before coming to decisions, I would like to consult as widely as possible on the options set out in this paper for structural change. I also want to take account of the emerging principles/criteria from the Executive's recently announced Review of Public Administration.

The acute hospitals review, now in its final stages, should not be seen in isolation. It is directly linked to work that I have commissioned covering: *Investing in Health*, which is the Executive's strategy for improving the health and well-being of the population; *Building the Way Forward in Primary Care*, a new approach to primary care; *Best Practice, Best Care*, which sets out proposals for improving the quality of services; and *Review of Community Care – First Report*, which is the first stage of a review of community care.

Taken together, these initiatives form the main components of a unified and coherent approach to improving health and social services. I intend to bring them together in a new Regional Strategy, which will be published next year.

The Executive's 2002-2005 Programme for Government commits it to developing proposals for a modern acute hospital service, with the declared expectation of taking decisions on the way forward in the course of 2002.

This is a challenging agenda for change, which will not be delivered overnight. However, we now have a robust strategy that will deliver a modern, caring, quality hospital and health care system. A system capable of delivering high-quality care and treatment today, and well into the 21st century.

Bairbre de Brún

Bairbre de Brún
Minister for Health, Social Services and Public Safety

RÉAMHRÁ AN AIRE

Choimisiúnaigh mé athbhreithniú ar sheirbhísí géarotharlainne i Lúnasa 2000, agus d'iarr mé ar an ghrúpa athbhreithnithe moltaí a dhéanamh ar phroifíl na seirbhísí otharlainne amach anseo, ag cur san áireamh ceisteanna rochtana, sábháilteachta, caighdeán cliniciúil agus cáilíocht seirbhísí.

Bunaíodh an t-athbhreithniú i gcomhthéacs an iliomad blianta de thearcmhaoinithe na seirbhísí sláinte, a bhain de agus a laghdaigh a n-acmhainn chun an cháilíocht seirbhíse a sholáthar atá de dhíth ar chóras otharlainne nua-aimseartha. Is é mo chuspóir clár oibre a fhorbairt le haghaigh nuashonraithe mhóir, atá i bhfad thar am, ar an chóras géarotharlainne.

D'aithin an Coiste Feidhmiúcháin an gá le caiteachas sláinte agus cúraim shóisialta a mhéadú agus d'infheistigh sé £523 milliún sa bhreis i gcúram sláinte ó bunaíodh an Tionól. Den mhéid sin, bhí 80% de dhíth le seirbhísí láithreacha amháin a chothabháil.

Cé go gcuirtear fáilte roimh an chaiteachas breise atá de dhíth go géar, ní hé caitheamh breise amháin an réiteach. Tá bunathrú ar an dóigh a soláthraítear agus agus riartar seirbhísí de dhíth má táthar chun córas otharlainne nua-aimseartha a sholáthar a fhreastlóidh ar riachtanais ár ndaoine uile. Mura ndéantar sin beidh seirbhísí againn a bheidh ag meath go fóill agus a thitfidh siar i dtaca leis na caighdeáin atá in áiteanna eile.

Sa pháipéar seo tá mé ag leagan amach an dóigh, a shílim, ar gá ár seirbhísí otharlainne a nuashonrú agus na cinní atá de dhíth leis na hathruithe seo a thabhairt chun tosaigh. Ní faoi ghéarsheirbhísí a laghdú atá mo mholtaí. Is é is aidhm leo, áfach, tógáil ar dhúshraitheanna láidre na seirbhísí faoi láthair chun cinntiú go bhfuil rochtain thráthúil ag cách ar ghéarchúram d'ardchaighdeán a sholáthraítear gar dá mbailte féin nuair is féidir.

Bheinn ag dúil go gcuirfeadh mo chuid moltaí seirbhís otharlainne nua, nua-aimseartha agus níos éifeachtaí i gcrích, seirbhís atá bunaithe agus a bhfuil acmhainní curtha ar fáil di chun freastal ar riachtanais líon ionchais na n-othar a mbeidh sí ag freastal orthu; go soláthróidís seirbhís den chéad scoth a bhfuil torthaí i bhfad níos feabhsaithe ann i réimsí ailse agus galar croí; an fhadhb le daoine ag feitheamh le hiontráil agus na scaoilte amach a bhfuil moill orthu a réiteach; freastal ar bhuaic-éilimh gan gnáthghníomhaíocht a chealú; agaí feithimh a laghdú ar dhóigh shuntasach, á dtabhairt anuas go tréimhse trí mhí ar a mhéad do chásanna neamhpháinneacha agus cóir leighis curtha ar chásanna tús áite i bhfad níos luaithe.

RÉAMHRÁ AN AIRE

Éilíonn soláthar cúram d'ardcháilíocht struchtúir eagraíochtúla a fhóireann don chuspóir agus ar féidir leo dul i ngleic leis na dúshláin atá os comhair seirbhís sláinte nua-aimseartha. Ba léir le tamall anuas an gá ann le haghaidh athchóirithe eagraíochtúil, ach is casta na ceisteanna ann. Sula ndéanfar cinneadh ar bith ba mhaith liom dul i gcomhairle a leithne is féidir ar na roghanna leagtha amach sa pháipéar i dtaca le hathrú sa struchtúr. Ba mhaith liom na prionsabail/critéir ag teacht chun cinn den Athbhreithniú ar Riarachán Poiblí ón Choiste Feidhmiúcháin a fógraíodh le gairid a ghlacadh san áireamh.

Níor chóir amharc ar an athbhreithniú ar ghéarotharlanna, atá ar na céimeanna deiridh, ina aonair. Tá nasc díreach idir é féin agus an obair a choimisiúnaigh mé a chlúdaigh: *Infheistíocht sa tSláinte*, arb é sin straitéis an Choiste Feidmhiúcháin le haghaidh sláinte agus folláine an phobail a fheabhsú: *An Bealach chun Tosaigh i bPríomchúram a Thógáil*, cur chuige nua i dtaobh príomhchúraim; *Sárchleachtas, Sárchúram*, a leagann amach moltaí le haghaidh cáilíocht na seirbhísí a fheabhsú; agus *Athbhreithniú Cúram Pobail – An Chéad Tuairisc*, an chéad chéim san athbhreithniú ar chúram pobail.

Is iad na tionscnaimh seo, tugtha le chéile, na príomhnithe i gcur chuige aontaithe agus chomhleanúnach chun seirbhísí sláinte agus sóisialta a fheabhsú. Tá sé de rún agam iad a thabhairt le chéile i Straitéis Reigiúnach nua, a fhoilseofar ar an bhliain seo chugainn.

Geallann an Clár um Rialtas 2002-2005 de chuid an Choiste Feidmhiúcháin é féin do mholtaí chun seirbhís géarotharlainne nua-aimseartha a fhorbairt, agus fógraíodh go bhfuiltear ag dúil le cinní ar an bhealach chun tosaigh a dhéanamh i rith 2002.

Is é seo clár oibre dúshlánach le haghaidh athraithe agus ní thar oíche a chuirfear i gcrích iad. Tá straitéis dhaingean againn anois, áfach, a sholáthróidh córas otharlainne agus cúram sláinte d'ardcháilíocht atá nua-aimseartha agus comhbhách. Córas a bheidh in ann cúram agus cóireáil a sholáthar inniu agus anonn go maith sa 21ú céad.

Bairbre de Brún

Bairbre de Brún
An Aire Sláinte, Seirbhísí Sóisialta agus Sábháilteachta Poiblí

CONTENTS

EXECUTIVE SUMMARY

Introduction

1. The ability of acute hospitals here to deliver safe, effective and timely acute services has come under increasing strain. Pressures for change are coming from many and varied directions - new patterns of illness and disease, new medicines and treatments, new technologies, new skills and changes in how doctors, nurses and other health professionals train and work. These changes, combined with years of under-investment, are placing sustained pressures on hospitals and their staff.

Why Change is Needed

2. Our pattern of hospitals is based on an outmoded approach to acute care. As medical practice has developed, the trend has been for health professionals to specialise and become expert in particular aspects of treatment and care. This has resulted in great advances in treatments and improved outcomes for patients.

3. There is also a great deal of evidence to suggest that outcomes are better where treatments and care are delivered by specialist, multi-disciplinary, teams. But such teams must be large enough to work effectively. The teams need to care for sufficient numbers of patients to make best use of their skills, and to maintain those skills throughout a lifetime of practice. This is particularly important, as all health care practitioners will, in the future, be required to demonstrate their continued professional competence on a regular basis.

4. Smaller hospitals are now finding it increasingly difficult to deliver services to modern standards. They are beginning to lose recognition as training hospitals, as they do not provide sufficient opportunity for health professionals to develop the skills and experience necessary, and some are now finding it difficult to attract and retain staff.

What Kind of Change

5. If our hospitals are to provide patients with the full benefits of modern medicine, they must change to make best use of new technologies and to support new working practices. The further concentration of acute services for patients with more complex conditions will greatly improve the quality of care and the outcomes of treatment.

6. However, concentration must be balanced against the accessibility of services for patients and their families. Developments in medicine and medical technology are also opening up the way for smaller hospitals to provide high quality diagnostic

services and a wider range of operations and medical procedures, often on an outpatient or day-case basis.

7. The effective delivery of services through managed clinical networks will, by supporting services across a number of sites, underpin a more convenient and accessible service for patients, without compromising standards of care or treatment.

Model for Future Hospital Services

8. Under the new model, none of the current hospitals delivering acute services will close - rather they will be adapted to support the new pattern of provision. The vast majority of people will be within 45 minutes, and everyone will normally be within one hour of emergency care and consultant-led maternity services. In the future, acute services will be more strongly patient-focused and organised around population groupings rather than facilities.

9. A number of new Local Hospitals will be established to deliver a wide range of services on a local basis. They will network with acute hospitals and local primary and community care to provide services that do not need to be delivered in a large acute hospital. The Local Hospitals will be the Mid-Ulster, South Tyrone, Whiteabbey, Downe, Lagan Valley, Mater and Tyrone County hospitals.

10. In view of the long journey times for some people, the Downe Hospital will be an Enhanced Local Hospital[1], and the provision of Enhanced Local Hospital services at Tyrone County Hospital is also proposed. As well as acting as a Local Hospital, Lagan Valley Hospital will become a specialist centre for planned (elective) surgery. Work will be undertaken to develop a second, protected elective centre in a Local Hospital west of the Bann.

11. There will be 9 acute hospitals at the Royal Group, Altnagelvin, Antrim, Belfast City, Causeway, Craigavon , Daisy Hill, the Ulster, and a new hospital in or to the north of Enniskillen. All of the 9 acute hospitals will support a broad range of acute services, each having their own characteristics and individual service profiles.

12. Consultant maternity in-patient services will be provided on 9 sites[2]. The development of midwife-led maternity units will be encouraged alongside consultant-led units, and 2 stand-alone midwife led units will also be piloted.

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[1] *See paragraph 4.22*

[2] *See paragraph 4.63*

13. Opportunities for co-operation between the North and South on a range of healthcare issues will be developed to their full potential.

Changes in Administrative Structures

14. It is essential that the organisational structures support a partnership approach between all parts of the Health and Personal Social Services (HPSS) and reinforce the effective and efficient delivery of services. A number of options for reforming the HPSS structures have been identified. These include:

- replacing the 4 HSS Boards;
- creating a single Regional Authority with responsibility for strategic planning, workforce planning and commissioning of regional services;
- bringing together Local Health and Social Care Groups as commissioning bodies for local health and social services;
- combining HSS Trusts or replacing them altogether; and
- replacing the 4 HSS Councils with a single, statutory health and social care consumer body.

15. Following consideration of responses to the proposals for structural change set out in this paper, further consultation will take place before decisions are taken on final configurations.

Equality Implications

16. A preliminary assessment has been carried out as to whether the proposals would have an adverse or negative impact on people in the Section 75 equality groups. This involved examining travel times under the current pattern of 15[3] acute hospitals and comparing these to travel times under the proposed 9 site model for acute services. Overall, the 9 site model for acute services would not appear to have a significant differential impact on any of the equality groups.

Resources

17. Substantial investment is essential to implement the proposals. Around £1.2bn of capital at today's prices will be required over a 9-year development period. The capital funding gap between the capital expected to be available over the period and what is required is estimated as £842m at today's prices.

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[3] South Tyrone hospital has temporarily losts its acute services pending the outcome of the Acute Hospitals Review

18. A significant increase in staffing will be needed to deliver these proposals: a 30% rise in the numbers of consultant medical staff; a 20% rise in qualified nurses; a 25% rise in other health professionals; and a 25% rise in doctors undergoing GP training. By 2010, the additional recurring funding required to support the increased workforce would be around £165m per annum at today's prices.

19. The new pattern of hospital services will lead to greatly improved performance, including reduced waiting times and the elimination of the problem of people waiting for admission and delayed discharges. While the Executive is committed to providing extra resources for hospital services, the extent and speed of that investment will be determined by the Executive, taking full account of available resources and relative priorities across all of its responsibilities.

CHAPTER 1: INTRODUCTION

1.1 The ability of acute hospitals here to deliver safe, effective and timely acute services has come under increasing strain in recent years. This reflects significant growth in the demands made on these services against a history of under-funding that has impeded service development over the past decade. At the same time, advances in medicine, medical technology, professional practice and standards of treatment have changed the nature of the services delivered by these hospitals.

1.2. It was against this background that the Minister for Health, Social Services and Public Safety commissioned an independent review of the current provision of acute hospital services.

1.3. The Acute Hospitals Review Group's (AHRG) report, published in June 2001, was subsequently issued for consultation. The report and the comments received covering its approach and conclusions have contributed to the proposals set out in this paper. The paper is structured as follows:

Chapter 2	Explains why change is needed.
Chapter 3	Explains what kind of change is required.
Chapter 4	Sets out a model for future hospital services.
Chapter 5	Sets out options for the changes in the administrative structures of the Health and Personal Social Services.
Chapter 6	Makes an initial assessment of the equality implications of the changes.
Chapter 7	Sets out the required resources and timing.

1.4. The proposals outlined in this paper have been discussed and agreed by the Executive for consultation. They will significantly affect the ways in which our hospital services are delivered, the ways in which staff do their work, the pattern of our hospitals, the range of services that they provide, and their accessibility.

Have your Say

1.5. The paper is being sent for comment to a wide range of organisations and individuals. It is also available direct to the public on request, and through libraries, health and social services premises and the Internet. The document is available in large type, braille, audio-cassette, Irish and Cantonese. Requests will be considered for translations into other minority languages.

1.6. If you want to express a view on the proposals set out in this paper, or on any of the issues it covers, you should write to, fax or e-mail the contact point below before 30 September 2002. In keeping with the Department's policy on openness, responses may be made available to the public. If you do not wish your response to be used in this way, or if you would prefer it to be used anonymously, please indicate this when responding.

1.7. Your views will help the Minister and Executive to reach final decisions on the future shape of hospital services and administrative structures. All the responses to the consultation along with any new information which might emerge out of, or during, the consultation, will be taken into consideration before final decisions are made on hospital services, around the end of November 2002, and before moving ahead with structural reform of the HPSS.

1.8. A telephone helpline for enquiries on how to obtain copies of the paper has been set up - the telephone number is (028) 9052 0210

1.9. Consultation meetings are being arranged at which people will have an opportunity to discuss the paper with representatives of the Department.

Contact Point

1.10. The central point of contact for all responses and copies of the paper is:
Department of Health, Social Services and Public Safety,
Modernisation Unit, Room C4.22, Castle Buildings,
Stormont, Belfast, BT4 3SG.
Tel: (028) 9052 2349
Fax: (028) 9052 0535
E-mail: modernisationunit@dhsspsni.gov.uk

Closing date for receiving comments

1.11. All comments should be submitted no later than 30 September 2002

CHAPTER 2: THE NEED FOR CHANGE

Background

2.1 Hospital services are facing critical and mounting problems. Too many people wait long periods for hospital treatment, and patients requiring emergency admission too often have to wait for a bed because hospitals are working to full capacity. With pressures on beds growing annually, peak pressures, previously associated with winter, are becoming a year-round problem.

2.2. It is also becoming increasingly difficult to keep services going in some hospitals, where the existence of small clinical teams means that services can be particularly vulnerable. Some services have failed in recent years; others are fragile and cannot be sustained much longer in their current form.

2.3. Hospital services have changed considerably in the past fifty years. However, the funding to match these changes has not kept pace and the necessary investment in these services has not been made. Too often, acute services are located in worn-out buildings, with staff doing their best to deliver 21st century treatments using outdated equipment and facilities.

2.4. This has led to the quality of some services falling. Hospital services must change radically if they are to achieve modern standards and to deliver the high quality care that people need. The following paragraphs outline the main pressures for change, the opportunities that are being created by new ways of working, and the drive to improve standards.

Pressures Facing Acute Services

2.5. Many of the pressures facing hospitals are inescapable and will, inevitably, affect the way future services are provided. Some fundamentally affect their ability to deliver safe and effective care.

Changing service needs

2.6. People are living longer. With advancing age, people are more likely to suffer from chronic diseases such as diabetes, heart disease or arthritic problems and may have two or more chronic health problems. They require continuing health care, co-ordinated and delivered by a wide range of health care staff in different places and at different times.

2.7. The expected growth in the number of elderly people here will give rise to substantial and increasing pressures on acute hospital services. Much more can be done for older people, who can now benefit from advances in medicine and surgery, including procedures such as renal dialysis, hip replacement or open heart surgery – treatments that would not have been available to them until relatively recently.

2.8. In addition to the increase in healthcare needs as a result of an ageing population, there are also more children and young people suffering from chronic diseases such as asthma and diabetes. Children today can also survive to adulthood with diseases such as cystic fibrosis. However, they may require regular and complex hospital-based treatments throughout their lives.

Developments in Health Care

2.9. New medicines to treat both chronic and acute illnesses are now available: chemotherapy for the treatment of malignant disease; advanced therapies, such as 'clot-busting' drugs, for the treatment of heart disease; and new medicines to relieve the symptoms of multiple sclerosis and rheumatoid arthritis. These treatments often replace older, less effective treatments, but usually at a higher price.

2.10. Many new treatments can now reduce short-term discomfort for patients or significantly improve their quality of life in the longer term. This is demonstrated by the significant increases in the number of hip replacements, cataract operations, coronary artery bypass operations, and organ transplants undertaken in recent years.

2.11. There have been many advances in surgical techniques. 'Key-hole' surgery has reduced post-operative pain and complications and accelerated recovery. Improvements in surgical techniques and anaesthesia have meant that more surgical procedures can be carried out on an outpatient or day-case basis, enabling patients to avoid long stays in hospital.

Developments in Medical Technology

2.12. Advances in medical engineering technology have also produced significant successes. For example machines (lithotripters) can generate shockwaves to smash stones in the kidney or urinary tract, and lasers can be used to destroy tumours and to eliminate clots in arteries. Medical imaging advances, such as CT and MRI scanners, and more recently PET scanners, will revolutionise diagnosis.

New ways of working

Specialisation

2.13. As medical practice has developed and widened it has become increasingly difficult, if not impossible, for doctors, nurses and other health workers to acquire knowledge and relevant skills in sufficient depth across the full range of health care services. As a consequence, they now train to develop narrower, more focused, interests in 'sub-specialties', in which they become expert.

2.14. Increased expertise has resulted in great advances in treatments and, most importantly, improved results for patients. For example, the advent of consultants specialising in spinal surgery, joint replacement or specialist hand surgery has directly improved outcomes for patients. However, it also means that the era of medical 'generalists', trained to span a wide range of specialties, is approaching its end. Such doctors have often provided the core of acute services in smaller hospitals here. As these doctors retire or move on, it is becoming impossible to replace them.

Information and Communications Technology

2.15. The information and communications technology revolution has the potential radically to improve medical diagnosis. It opens the way for much better use of information, through a greater integration of systems. This will mean that information held in different locations can be combined to gain a fuller understanding of the progression of illnesses and the effectiveness of treatments, thus supporting the development of new and more effective practice.

2.16. The developing ability to shrink distances through advanced communication systems will also transform how hospitals work. Telemedicine, for example, allows a GP to transmit a photograph of a patient's skin condition to, and receive advice from, a dermatologist who may be located hundred of miles away. Similarly, if a patient has severe chest pain, the technology to transmit a patient's heart tracing (ECG) to a cardiologist by cellular telephone for expert advice is already in use.

A Team Approach

2.17. People often seek help with healthcare problems that do not fit within a single specialist area. Patients with chronic diseases, affecting many body systems, are becoming more common. Health care practitioners of all types need to work in teams, pooling their knowledge and skills to provide the best available care for such patients.

2.18. There is a great deal of evidence to suggest that outcomes are better if treatments and care are delivered by specialist multi-disciplinary teams. This is particularly so in the delivery of cancer services, but has also been shown to be the case for many chronic diseases. It is now accepted that services are better if they can be organised in a way that allows multi-disciplinary teams to develop.

2.19. Such teams must be large enough to work effectively and to provide reasonable working conditions for all the staff involved. They also need to care for sufficient number of patients to make best use of their skills and to maintain those skills throughout a lifetime of practice. This is particularly important, as all health care practitioners will be required to demonstrate their continued professional competence on a regular basis.

Training

2.20. The healthcare workforce is highly skilled, with one in five a graduate in their professional discipline. However, graduation is only the first rung on the ladder to specialist practice. Training takes place largely within the health service over several years. Traditionally this has mainly involved learning on the job. There have been significant changes to this approach throughout the past decade, which have recognised that it is not the most efficient way of equipping staff for specialist practice.

2.21. Increasingly, the jobs available to junior doctors, and other professional staff, do not provide the opportunity to develop the skills and experience necessary for modern practice. More stringent requirements covering the degree of supervision, the specific nature of the work undertaken by trainees and facilities for study available, are being applied by professional standard-setting bodies when considering, or reviewing, the suitability of a post for training.

2.22. The acute sector has been heavily reliant on staff in training to supplement the provision of patient care. This can no longer continue. At present, in hospitals which cannot meet training needs, the loss of training recognition has the potential to critically undermine service provision.

Supporting Hospital Staff

2.23. The hospital service depends on the commitment and motivation of its staff to deliver the quality of care achieved. Staff often work long hours, frequently beyond their contractual commitments, in the interest of their patients. They may work in a less than ideal environment, and find themselves dealing with situations that can be harrowing and disturbing. They do so with professionalism and dedication.

2.24. It is important that the commitment and motivation of staff is built upon rather than undermined. If the current organisation of acute services does not provide staff with adequate support in an acceptable physical environment, there is a significant risk that:

- local recruitment of doctors, nurses and other health professionals will become increasingly difficult;
- staff will leave to find jobs elsewhere; and
- international recruitment will become progressively less fruitful.

Improving Standards

2.25. Improving the quality of hospital care, and the environment in which this care is delivered, is a major priority. The responsibility for quality has been addressed at both an individual and a corporate level. Individual doctors, nurses and other health professionals must now ensure that their professional development keeps their knowledge and skills up to date. At a corporate level the duty on Trusts to provide quality care will soon become a statutory responsibility. Accountability for the delivery of the services will be strengthened through the introduction of robust clinical and social care governance arrangements.

2.26. These requirements, along with new arrangements for the production and dissemination of standards, will ensure that individual members of staff will be kept fully up to date with guidance on new technologies and standards for treatment to be applied. All of this will be underpinned by a transparent and open system of independent monitoring of the quality of services within the HPSS. The principal vehicle for this will be the planned Health and Social Services Regulation and Improvement Authority, which will be established subject to the will of the Assembly, with legislation being brought forward this autumn.

Conclusion

2.27 There have been major changes in the needs of the population, and in medical knowledge, medical technology and the way doctors, nurses and other health professionals train and work to deliver acute healthcare. The public rightly expects the highest standards of services, and these need to continue to improve. All of these factors, taken together, will have a profound effect on the way hospital services can be provided in the future.

2.28. The hospital service is constantly changing. Thanks to its highly skilled and committed workforce, hospitals continue to deliver good quality services, despite the growing pressures, and will continue to strive to do even better. However, it is increasingly difficult to deliver safe, modern and effective services in ageing hospitals, with outdated equipment and staffing complements that cannot support best clinical practice.

Pressures for Change

- Ageing population requiring increased treatment and care
- New medicines and new treatments
- Developments in medical technology
- New ways of working
- More stringent training requirements
- Improving standards

CHAPTER 3: WHAT KIND OF CHANGE

3.1 At present, there are 15 hospitals providing acute services here (see map at Appendix 1) and one further hospital that has temporarily lost its acute services, serving a population of around 1.7 million people. They range in size from large acute hospitals, such as the Royal Group and the Belfast City Hospitals, each serving the Belfast area and the whole population in some regional specialties, to the Downe hospital, serving a local population of around 55,000 people.

3.2. In order to meet the pressures for change outlined in the previous chapter, there needs to be a radical re-shaping of acute hospital services, with a greater differentiation between the roles of the current range of hospitals, concentrating specialised services where necessary, and decentralising other services where possible.

3.3. The trend internationally has been towards a greater concentration of hospital services on fewer sites. A number of professional medical bodies, including the Royal College of Surgeons, consider that an acute hospital, providing a full range of facilities and acute specialties, should be sufficiently large to serve a population of around 450,000-500,000 people. This would equate to three acute hospitals here. In practice, they recognise that most acute hospitals will continue to serve populations of around 200,000-300,000 for the foreseeable future.

3.4. It is their view that the specialist teams and technology necessary to treat acutely ill patients, and those with complex conditions, can only be maintained in large hospitals serving substantial numbers of patients. Such hospitals can be staffed to deliver complex modern treatments, ensure proper under-graduate and post-graduate professional training and raise clinical standards. Patients benefit by being treated by professional teams that treat enough patients to develop and maintain expert skills across a wide range of subspecialties.

3.5. Larger facilities are considered better able to use sophisticated diagnostic and other support services efficiently and economically, and support the number of clinicians necessary to provide 24 hour medical cover.

3.6. The Acute Hospitals Review Group and earlier reviews of acute services, conducted by the Health and Social Services Boards, have separately concluded that, to improve services for patients, a further concentration of acute services is necessary here.

Providing Local Services where Possible

3.7. Such reviews have also acknowledged that the improved quality of care and treatment arising from concentrating acute services must be balanced against the accessibility of these services to patients and their families. People want the best services available but prefer to have these in their own local area unless there is a good reason to travel further. They also want prompt and ready access to life-saving treatment in the event of an emergency.

3.8. Local hospitals foster the development of relationships with community and primary care services. Moreover, with developments in new technology such as telemedicine and teleradiology, local hospitals can now more easily link to specialist advice and support in larger acute hospitals. These developments in technology open the way for these hospitals to draw on medical and other expertise at a distance, and to provide patients with better diagnoses, of a potentially higher quality and with a minimum of delay.

3.9. The advances in medical treatment also mean that many more, formerly specialised, operations and medical procedures are becoming 'routine'. These can be more readily de-centralised and can often be treated on a day procedure basis.

Managed Clinical Networks – A New Way of Working.

3.10. In looking at how acute hospitals may change, it is important to take account of the advent of Managed Clinical Networks. Although still in its infancy, this approach to collaborative working opens the prospect of re-focusing services on populations rather than facilities.

3.11. The Acute Hospitals Review Group report noted the potential benefits of managed clinical networks and, in particular, *"their ability to facilitate the concentration of specialist skills and complex diagnostic equipment, when appropriate, without necessarily having to close down local services which are so highly valued by local communities".*

3.12. Managed Clinical Networks have the potential to provide services to patients in a different way. They will support doctors, nurses and other health professionals, working together across different facilities and geographical/organisational boundaries to provide the right care for patients delivered from the most suitable location.

3.13. An effective clinical network for hospital based cancer services is already operational here. Staff at Cancer Units in Antrim, Craigavon, Altnagelvin and the Ulster hospitals work with the Belfast Cancer Centre to ensure that all patients receive high quality care. Regular multi-disciplinary meetings at the Cancer Centre and the Cancer Units provide the opportunity for health professionals to discuss an individual patient's diagnosis, and to agree the best medical or surgical care for that patient.

3.14. By providing services across a number of sites a more convenient and accessible service is provided for patients, without compromising standards of care or treatment. For example, a surgeon may provide outpatient clinics in a local hospital, carry out day-case surgery in a designated elective facility and perform major inpatient surgery at a large acute hospital.

3.15. Networks depend not just on individuals working across sites but on all the health professionals and their organisations working together to share good practice, communicate with one another, and provide a seamless service to patients. They offer the possibility of organising services differently, with the prime focus on the needs of the patient.

Conclusion

3.16. To support the development of modern hospital services, acute services here must change. Our pattern of hospitals is based on an outmoded approach to acute care. This does not facilitate the development of robust modern services that are sustainable and able to provide patients with both the full benefits and the level of quality of outcome which modern medicine can provide.

3.17. There is a limit to how much re-adjustment can be made to the current pattern of acute hospital services, and smaller hospitals are now finding it increasingly difficult to deliver services to modern standards. Consequently, they are beginning to lose training recognition and some are now finding it difficult to recruit and retain staff.

3.18. Action is needed now to identify where and in what ways services need to be concentrated to achieve higher quality; and where they can be decentralised, to make them even more accessible. A new pattern of services, supported by innovative managed clinical networks, will make an important contribution to transforming the quality and responsiveness of hospital services.

CHAPTER 3: WHAT KIND OF CHANGE

Re-shaping Acute Services

- Concentrating services can bring considerable benefits
- Benefits of concentration must be balanced against accessibility
- De-centralisation of more hospital services now possible
- Managed Clinical Networks can support more convenient and accessible services

CHAPTER 4: A MODEL FOR FUTURE HOSPITAL SERVICES

Current Arrangements

4.1. At present, the acute hospitals here all deliver a wide range of acute inpatient, day-patient and outpatient acute medical and surgical services. All but one of the hospitals have an A&E department and thirteen of them provide in-patient maternity services, with the number of deliveries ranging from around 450 to 5000 each year.

4.2. Serving a population of around 1.7 million people, these hospitals each year treat around 380,000 in-patients, 150,000 of whom are emergency admissions, and 120,000 day-patients. They also manage 1,200,000 outpatient and 670,000 A&E attendances.

4.3. The factors outlined in previous Chapters underline the need for significant change in the way hospital services are delivered in the future. The challenge is to build on the strengths of the current service, and to develop a modern and effective hospital service that meets the needs of patients, and delivers the full benefits that modern medicine can offer.

4.4. To meet these requirements will require a shift away from stand-alone hospital facilities towards an integrated service that delivers a comprehensive range of treatment and care from a variety of hospital and primary care settings, all operating collaboratively as an inter-dependent care network.

Principles

4.5. In seeking to achieve the right relationship between quality, safety, accessibility, sustainability, equity, and affordability, the proposals in this Chapter are guided by the following principles:

- none of the current hospitals offering acute services should be closed – rather, they must be adapted to play their part in a new configuration of service provision;
- services should be decentralised wherever the opportunities created by service and technological developments make this possible and sustainable;
- the range and quality of hospital services should aim to match the best standards achieved in other parts of Europe;
- access times to emergency care and consultant-led maternity services, in an appropriate facility, should be the minimum achievable, with the vast majority of people within 45 minutes, and everyone normally within one hour, of these services; and

[redacted]

- acute services must be re-focused, to achieve the concentration of expertise and experience required to deliver the highest possible levels of clinical care.

A systematic Approach to Hospital care

4.6. In developing these proposals, account has been taken of the AHRG report and the outcome of the public consultation on its findings. They follow a similar approach to the AHRG recommendations, in that they are built around a network of acute hospitals and Local Hospitals. However, the proposals go further than the AHRG recommendations in that they do not categorise acute hospitals into different levels and open the way for:

- the provision of a second Enhanced Local Hospital, in the West;
- the provision of a second protected elective centre, west of the Bann; and
- the piloting of two mid-wife led stand-alone maternity units, one in the East and the other in the West.

4.7. The hospital service has to be developed as an integral part of the total health system. Hospitals need to work as a dynamic element of that system, if they are to function effectively. The hospital service ultimately relies on primary and community care services, working effectively to channel the right patients to it and to re-integrate them back into the community at the end of their acute treatments.

4.8. The approach set out in this Chapter is based on the expectation that acute services will be patient -focused and organised around population groupings rather than facilities. This will require a much greater movement of staff within the system to support local activity and to ensure the proper decentralisation of services.

The Approach

- Closer integration of primary, community and secondary care
- Patient-focused acute services, organised around populations
- Greater movement of staff within system
- Local Hospitals a vital bridge in the new integrated health system

Links to Primary and Community Care

4.9. The boundaries between primary and hospital care are becoming increasingly blurred. Primary Care Teams, which bring together GPs and community health and social care professionals, including pharmacists and general dental practitioners, are most often the first point of contact that people have with the Health and Social Services. They play an increasingly important role in sustaining vulnerable and chronically ill people in the community, and managing their access to appropriate levels of acute care.

4.10. This role is set to expand, with the development of Local Health and Social Care Groups providing a better focus for modernising primary and community care.

4.11. The further enhancement of primary care will directly support the localisation of services, with an increased emphasis on providing them as close as possible to the people relying on them. In addition to established relationships with existing community hospitals, such as Ards and Bangor hospitals, primary care teams will have the opportunity to work closely with Local Hospitals, which will form a bridge between acute and primary care.

4.12. Given proper investment, it is envisaged that primary care, secondary (hospital) care and community care professionals will work together, in modern facilities, to provide the vast majority of hospital and community services required by the local communities that they serve.

A New Model for Hospitals

- Strikes the right balance, proposing a network of acute hospitals and Local Hospitals, including:
    - ➤ 9 acute Hospitals
    - ➤ 2 Enhanced Local Hospitals
    - ➤ 2 protected elective facilities
    - ➤ 9 consultant-led maternity units
    - ➤ 2 pilot stand-alone midwife-led maternity units
- Links to primary and community care

New Local Hospitals

4.13. In providing an effective health care system, local access to services is important. **Local Hospitals** will work directly in partnership with acute hospitals, forming a crucial bridge between hospital and primary and community care and helping to achieve cohesion between the different care sectors.

4.14. Local Hospitals are an important new concept, building on recent service developments here and elsewhere. They will be developed to provide the vast majority of services that people get in hospital settings (some 70%), and that do not need to be delivered in a large acute hospital.

4.15. Developments in clinical practice and technology are making more local treatment and care increasingly possible. Many investigations, treatments and procedures, previously requiring hospital admission, can now be carried out effectively and safely outside a major acute hospital.

4.16. Local Hospitals will provide increasingly sophisticated methods of investigation, diagnosis and day procedures that go considerably beyond what is currently available from Community Hospitals. They will provide a local base for expert clinicians, specialist nurses and other health professionals, who will relate to local populations rather than to individual facilities and provide a wide range of services, including:

- Extended-hours access to a minor injuries unit,
- an increased range of day case surgery,
- a wider variety of high quality diagnostic services,
- a wider range of outpatient clinics,
- pre and post natal maternity services,
- intermediate care, and
- rehabilitation and step-down beds, supporting people who require less intensively supported care as they complete their recovery from in-patient treatment.

4.17. The accessibility of Local Hospitals, their size and their local character, will ensure that they make a distinctive contribution to the overall provision of modern, high quality hospital services.

4.18. Developing Local Hospitals in this way will require considerable and continuing investment in modern equipment and in the training of staff. However, the proper development of Local Hospitals will greatly benefit the people who make use of their services.

4.19. The Mid-Ulster, South Tyrone , Whiteabbey, Downe, Lagan Valley, Mater, and Tyrone County hospitals will be developed as Local Hospitals. To take account of local circumstances, a number of these will have some additional services, as set out in the following paragraphs.

Downe Hospital

4.20. The AHRG report proposed that the Downe should provide, among other things, a 24 hour A&E service and emergency medical service, including coronary care. It should also provide planned (elective) day procedures but not emergency surgery.

4.21. This model raises a number of issues relating to the nature, extent and sustainability of the proposed services at the Downe. To address these, further clarification was sought regarding the detail of the model and the journey times in the Down area.

4.22. Journey times from some districts served by the Downe to the nearest acute hospital can be as much as 55 to 60 minutes. It is therefore proposed that the Downe should provide some additional services, as an **Enhanced Local Hospital**. The hospital will be linked to the acute hospital network and supported to maintain a 24 hour A&E unit, capable of providing resuscitation and emergency coronary care, and a consultant-led in-patient medical service, in addition to out-patient, diagnostic and day procedures.

4.23. In proposing this Enhanced status for the Downe as a Local Hospital, account has been taken of the particular problems of delivering emergency services to the dispersed rural population relying on this hospital. This approach builds on a model for the hospital previously developed by the Eastern Health and Social Services Board in collaboration with the Down Lisburn Trust, and the hospital consultants who provide current services at the hospital and in Belfast.

4.24. This hospital will have to work as part of a clinical network if it is to sustain these additional services. This will be challenging for staff at the Downe hospital and the acute hospitals working in partnership with it. The approach will be evaluated on a regular basis to confirm its continuing viability.

4.25. The consultant-led inpatient maternity services provided by the Downe will be transferred, in line with proposals on Maternity services later at paragraph 4.61.

Tyrone County Hospital

4.26. A new Local Hospital is proposed for Omagh. Analysis of the journey times to an acute hospital in or to the north of Enniskillen shows that some people served by the Tyrone County Hospital would have journey times approaching 60 minutes.

4.27. Recognising that traffic volumes and other factors may also push journey times over the hour at certain times of the day, it is proposed to site an Enhanced Local Hospital in Omagh. The Western Health and Social Services Board will be asked to lead a process involving local Trusts, clinicians, other hospital staff, and other interested parties, including service users, to develop a model for such an enhanced service.

4.28. The model will need to demonstrate that any proposals are viable, sustainable and will not undermine the new acute hospital in the area.

Lagan Valley Hospital

4.29. Recognising the current capacity problems in Belfast, Lagan Valley Hospital will have to continue to provide a wide range of acute services for much of the period leading to the establishment of a new pattern of hospital services, pending its transformation to a modern Local Hospital.

4.30. As a Local Hospital, Lagan Valley Hospital will have a minor injuries unit linked to one of the Belfast A&E centres, and a rehabilitation role, particularly for local older people. It will also provide state of the art outpatient and diagnostic services for the major specialties.

4.31. Given its location and facilities, it is proposed that the Lagan Valley Hospital becomes a specialist centre for planned (elective) surgery for Greater Belfast , protected from short-term emergency pressures and developed so as to maximise its elective capacity. This would facilitate the development of elective beds, allowing the hospital to make a significant contribution to decreasing waiting times for surgery in the East.

Other Protected Planned Admissions Provision

4.32. A single protected centre of this type, located adjacent to the Greater Belfast area, is unlikely to be sufficient to meet needs, reduce waiting lists, and ensure equality of access.

4.33. There exists a particular sense of inequity west of the Bann. Public concerns that services have been run down, withdrawn and made less accessible have generated understandable fears of being left without services.

4.34. Noting that accessibility is an important consideration, further work will be undertaken by the Department to identify a second major protected elective centre in a Local Hospital west of the Bann. In conjunction with other proposals in this paper, this centre will provide an important contribution to decreasing waiting lists in the West.

Mater Infirmorum Hospital

4.35. Recognising the current capacity problems in Belfast, the importance of making full use of the modern facilities of the Mater hospital is accepted. The Mater must therefore continue to provide a range of acute services for much of the period leading to the establishment of a new pattern of hospital services, pending its transformation to a modern Local Hospital. The Mater has a long and distinguished history as a teaching hospital. As a new Local Hospital, with good clinical links to the Royal Group of Hospitals and the Belfast City Hospital, and in close proximity to them, the Mater will be ideally placed to play an even more significant role in contributing to training of doctors, nurses and other health professionals of the future.

4.36. To enable the hospital to make this vital contribution, the Mater Hospital will be further supported in developing and expanding its role as a key institution in the fields of medical and nurse training. In particular the Department will formalise its role as a teaching hospital by putting its links with Queen's University on a statutory basis in the same way as the two main teaching hospitals. As a result the University would be given representation on the Trust board. These arrangements will be reviewed as necessary in the light of the decisions taken on HPSS structures.

4.37. The Mater has been experiencing increasing difficulties in maintaining the existing maternity services. The Mater's close proximity to the new centralised maternity hospital[4] may, however, open up opportunities for sustaining the service on a close partnership basis.

4.38. The AHRG concluded that: *'inpatient and other maternity services should only be maintained at the Mater on the basis of the continuation and development of existing links with the Royal Jubilee unit, including close networking and adherence to joint clinical protocols. This would involve rotation of the consultants, midwifes and junior medical staff in the two maternity units who would effectively act as a single clinical team.'*

4.39. It is proposed, on the basis of the approach suggested by the Acute Hospitals Review Group, that maternity services at the hospital will be maintained. This will be conditional upon the Mater Trust working with the new centralised Belfast maternity service, to show that robust networking arrangements can be put in place and sustained.

Modern Acute Hospitals

4.40. It is proposed to create a stable pattern of modern acute hospitals, comprising nine acute hospital sites. This approach will ensure that, regardless of where they live, most people will have access to acute services, effective emergency care and consultant-led maternity services within 45 minutes, and all the population will normally be within one hour of these services.

4.41. A core element of this approach is the establishment of a more integrated and mutually supportive network of acute and local hospitals. This will provide an inter-locking and seamless high quality care hospital network that links directly to primary and community care arrangements.

4.42. Some 'regional' services, such as chemotherapy, have already been decentralised from the Belfast hospitals. Future moves, such as the development of consultant-led fracture clinics in all acute hospitals, and full in-patient fracture services at Antrim and Craigavon, will also be brought forward.

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[4] *A new Centralised Maternity Service will be sited on either the Royal Group or the Belfast City Hospital site. Maternity services at the Mater Hospital should link directly to this Service.*

4.43. In addition Musgrave Park Hospital will continue in its role as a regional orthopaedic centre providing protected elective orthopaedic procedures. Steps will be taken to enhance services at the hospital, to facilitate a reduction in current long waiting times for operations.

4.44. Commissioners and providers of services will be expected to continue to pursue decentralisation opportunities as and when medical and technological advances permit.

4.45. Future acute services will be provided from nine hospitals: Royal Group, Altnagelvin, Antrim, Belfast City, Causeway, Craigavon , Daisy Hill, Ulster, and a new hospital in or to the north of Enniskillen, to serve the Fermanagh/Tyrone area. The rationale for the location of the new hospital for the Fermanagh/Tyrone area is addressed in paragraphs 4.51-4.60 below.

4.46. These acute hospitals will each have their own characteristics and individual service profiles. They should be seen as part of a mutually supportive network of complementary services. All of the nine acute hospitals will support a broad range of acute services. Each will have 24 hour A&E services, and a wide range of in-patient, outpatient and day procedures. Eight of the nine will have consultant led in-patient maternity services[5]. These services will meet most of the acute service needs of the population.

4.47. Additional specialist services, for the minority of patients with severe or complex conditions that require very specialist care, will be provided from some of the acute hospitals with larger patient volumes, for example inpatient fracture surgery. Where a patient requires services that are not provided in the acute hospital closest to their home, they will be admitted directly to, or transferred to, the nearest facility providing such services.

4.48. To provide patients with modern and effective treatments to the highest standards, specialist services need to be resourced accordingly. To deliver them, acute hospitals require the facilities, equipment and specialist medical, nursing, health professional and other support staff necessary to provide a multi-disciplinary approach to the management of complex clinical treatments.

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[5] *A new Centralised Maternity Service will be sited either on the Royal Group or the Belfast City Hospital site.*

4.49. There are a small number of services, such as neurosurgery or renal transplantation, which are distinguished by their highly specialised nature or by the relatively low number of patients, often with rare or complex conditions, that they treat. These will only be provided, on a region-wide basis, from one or two of the acute hospitals.

4.50. In addition, a number of Belfast hospital based specialties will be re-located, in line with the recommendations of the Eastern Health and Social Services Board's report: *Taking forward the Pattern of Acute Hospital Services in the Eastern Board Area, (December 2000).* These cover the future siting of specialties covering Plastics, Dermatology and Rheumatology. In the case of paediatric and adult ENT services, appropriate account will be taken of subsequent work by the Board with Trusts and clinicians on the separate siting of these services.

A New Fermanagh/Tyrone Acute Hospital

4.51. A new acute hospital in the Fermanagh/Tyrone area is necessary to provide accessible, high quality services to people in that area.

4.52. An acute hospital must have a workload sufficient to ensure its long-term viability. The Department's assessment is that a new acute hospital, at any of the locations considered, is sustainable, provided it is part of a larger managed clinical network. Potential partnership arrangements with acute hospitals in the South would further support the sustainability of an acute hospital in Fermanagh/Tyrone area.

4.53. The choice of locating the hospital in or to the north of Enniskillen, in Omagh, or in a location elsewhere, was finely balanced, and further analytical work was undertaken to guide this decision.

4.54. The over-riding concern was to ensure that the new facility meets the acute service needs of the population. The consultation on the AHRG report generated a number of detailed proposals as to the location of the new hospital and information was provided in support of each location.

4.55. To further inform the decision-making process, some additional analysis was undertaken in assessing journey times within Fermanagh/Tyrone and between the counties and adjacent hospitals in the South (See Appendix 5). An independent review and analysis of the reports supporting a number of locations/sites was commissioned; and activity and staffing data, covering Sligo, Cavan, Monaghan and Letterkenny hospitals, were analysed to help to establish the current potential of these hospitals to contribute to the provision of acute services here. Deprivation indices were also reviewed.

4.56. The results of these analyses can be summarised as follows:

(i) If the use of hospitals in the South is not taken into account and a new Fermanagh/Tyrone hospital is situated in or to the north of Enniskillen, around 8,744 people in the Fermanagh/Tyrone area would have travel times of over 45 minutes, of whom 2,131 would be between 50 and 55 minutes travelling time from the hospital. None would be more than 55 minutes away from the hospital. This compares with an Omagh location where 24,250 people in the Fermanagh/Tyrone area would be more than 45 minutes away, of whom 21,234 would be more than 50 minutes away, with 9,749 more than 60 minutes travelling time from the hospital. A location at Ederney, a location half way between the two towns, would place 17,802 people in the Fermanagh/Tyrone area more than 45 minutes away from the hospital, of whom 7,260 would be between 55 and 60 minutes travelling time away from it, and none would be more than 60 minutes away.

Site	**Total no in Fermanagh/ Tyrone with journey time over 45 mins#**	**Of those with journey time over 45 mins**		
		Journey time Over 50 min	**Journey time Over 55 min**	**Journey time Over 60 min**
Enniskillen*	8,744	2,131	0	0
Omagh	24,250	21,234	9,749	9,749
Ederney	17,802	7,260	7,260	0

** Times are calculated on the current hospital. If the new hospital was to the north of the town, journey times would be reduced.*

 # Calculations assume that people will travel to their nearest hospital in the North for treatment. While this may be the case for Accident and Emergency attendances, patients will travel to other hospitals for elective treatment, particularly for certain specialities

(ii) If hospitals in the South were able to provide A&E and a full range of acute services to the population, and if this were factored into travelling times, no-one in Fermanagh or Tyrone would have to travel more than 55 minutes to an acute hospital, regardless of the location chosen. In this scenario, the differences between access times are much closer. If the hospital is located in or to the north of Enniskillen, around 6,525 people in the Fermanagh/Tyrone area would have travel times of over 45 minutes, none of whom would be more than 50 minutes away from the hospital. This compares with an Omagh location where 4,626 people would be more than 45 minutes away, of whom 2,365 would be between 50 and 55 minutes away from the hospital. A location at Ederney, which is half way between the two towns, would place 4,072 people more than 45 minutes away, none of whom would be more than 50 minutes travelling time away from the hospital.

Site	Total no in Fermanagh/ Tyrone with journey time over 45 mins#	Of those with journey time over 45 mins		
		Journey time Over 50 min	Journey time Over 55 min	Journey time Over 60 min
Enniskillen*	6,525	0	0	0
Omagh	4,626	2,365	0	0
Ederney	4,072	0	0	0

**Times are calculated on the current hospital, if the new hospital was to the north of the town, journey times would be reduced.*

 # Calculations assume that people will travel to their nearest hospital in the North or South for treatment. While this may be the case for Accident and Emergency attendances, patients will travel to other hospitals for elective treatment, particularly for certain specialities.

4.57. There has been communication at a senior level between the Department of Health, Social Services and Public Safety and the Department of Health and Children concerning the potential of hospitals in the South to provide services to patients from the North. From this, it is apparent from the current stage of planning for hospital services that there is uncertainty as to whether the relevant hospitals in the South will deliver, over the longer term, the capacity and services equivalent to those provided by the nine acute hospitals in the North. This degree of uncertainty has to be taken into account in deciding the best location of the new hospital with a potential life-span of 60 or more years.

4.58. The revenue and capital costs of the new hospital would be largely the same whether it is located at Enniskillen, Omagh or a location somewhere between the two towns. However, some additional infrastructure costs, for example for services and road improvements, may be required if the hospital is located well outside the two main towns.

4.59. Given the difficulties that the Erne and Tyrone County hospitals are currently experiencing in maintaining acute services, it is essential that a decision on the location for the new hospital is reached as quickly as possible. In these circumstances and on the information available, the balance of advantage lies in locating the new hospital in or to the north of Enniskillen.

4.60. This proposal is firmly based on the available information, and any new information that emerges during the course of the consultation will be taken into consideration before reaching a final decision.

Maternity Services

4.61. Women want maternity services that are safe, provide high quality care, and offer real choice in the range of care available. They are particularly concerned about having to travel long distances during pregnancy or labour.

4.62. It is the intention that maternity services should be provided as close to people's homes as possible. Consequently, Local Hospitals, as well as the acute hospitals, will provide ante-natal care, ultrasound screening, assessment of complications and post-natal care for mother and baby.

4.63. Moreover, all mothers-to-be should normally be within one hour of the nearest consultant-led maternity unit. The safety of mother and baby is paramount, and women need to have confidence that safe and satisfactory arrangements are in place for their care and support in all maternity units. All of the 9[6] consultant-led maternity units will therefore provide cover, on a 24 hour basis, supported by teams of consultant obstetricians, consultant anaesthetists and consultant paediatricians.

4.64. It is clear that, in the future, the number of expectant mothers who will deliver their babies in the smaller maternity units will not be sufficient to enable staff in these units to maintain their expert skills. In such units, the small numbers of deliveries make it impossible to sustain the full team necessary to deliver a consultant-led maternity service.

4.65. Alongside the concentration of consultant-led maternity services, delivered on fewer sites, the development of midwife-led units, within or adjacent to a consultant-led maternity unit, will be taken forward. Such units can allow mothers with a low risk of having a complicated labour, to have a more natural birth in a safe but homely environment. The further development of these units will be actively promoted.

Midwife-led Stand Alone Units

4.66. The opportunities to move beyond this approach towards stand-alone midwife-led units are already being demonstrated in pilot schemes, in England, Wales and the South. Preliminary evaluations indicate that such units are capable of providing a safe, alternative option of care during delivery for mothers-to-be who are assessed as 'low risk', by putting in place appropriate and effective transfer arrangements to cover unexpected emergencies.

4.67. The opportunities for such developments here should be fully explored. It is proposed that the Department, in consultation with HSS Boards and Trusts, will arrange for local pilot projects to be established. Two initial pilot schemes are envisaged, one in the East and one west of the Bann. The proposed pilots will establish clear protocols to ensure that, where risks are identified at any stage, mothers-to-be are referred to a consultant-led maternity unit, which will be supported by the establishment of an effective region-wide neonatal transport service. The training and skills of midwives in the Stand Alone Units will also be enhanced.

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[6] *A new centralised maternity service will be sited on either the Royal Group or Belfast City Hospital site. Maternity services at the Mater should link directly to this.*

Supporting Rural Communities

4.68. The development of Local Hospitals, working with appropriately sited acute hospitals, will ensure that rural communities are not disadvantaged when it comes to accessing hospital services.

4.69. Recognising that, no matter how hospital services are arranged, dispersed rural communities will be some distance from them, early additional steps will be taken to put in place supporting measures. These will add to and complement the provision of hospital services and ensure that the needs of rural people are adequately addressed. These include:

- **Rapid Responder Schemes**– providing 24 hour cover within defined geographical areas. These are ambulance service paramedical staff, with pre-hospital trauma and life-support skills. Using rapid response vehicles, they will respond to emergency calls, assess the situation, and either deal with the incident themselves or provide support and care until an ambulance arrives;

- **First Responder Schemes** – these schemes provide a network of local people with the skills to respond to life-threatening emergencies;

- **Improved Ambulance Services** – the Department's plans will improve ambulance response times for many rural areas, and ambulance crews will be trained to provide thrombolysis (clot-busting drugs) for appropriate patients before they arrive in hospital;

- **Transport services** - a more flexible interpretation of 'clinical need' will be applied when considering eligibility for transport to and from hospital provided by the HPSS for people in rural areas; and

- **Innovative planning** –Boards and Trusts will set up task groups to develop imaginative ways of addressing the problems that people in rural areas face, especially those areas with long and difficult journeys. Examples include making greater use of vehicles other than ambulances for patients who do not require skilled ambulance aid, and enhancing services provided by primary care teams, drawing on the expertise of other emergency services.

4.70. The aim is not to substitute local services for hospital-based care but to develop a range of pre-hospital support services, to ensure that the overall service available to rural communities is as good as that available to people living in communities closer to hospitals. The service for each area will be tailored to meet particular local circumstances.

Working in Partnership with the South

4.71. The AHRG recommended that collaborative working with health services in the South should be encouraged. This is fully in keeping with work already agreed and in progress.

4.72. For example, in 2000 the North South Ministerial Council (NSMC), established the North South Regional Hospital Services Group (NSRHSG) to consider the opportunities for developing partnerships covering the wider regional and supra-regional services. It has been tasked with identifying service areas/specialities where cross border or all-island co-operation can be of mutual benefit.

4.73. Cooperation and Working Together (CAWT) is an organisation formed in 1992 to promote cooperation in improving the health and social well-being of the populations of the North Eastern and North Western Health Boards in the South, and the Southern and Western Health and Social Services Boards in the North. A number of local cross-border initiatives are being developed by CAWT, which has been exploring opportunities for building greater collaboration between hospitals in border areas.

4.74. The Health Departments here and in the South are working collaboratively on A&E services, planning for major emergencies, co-operation on high technology equipment, cancer research and health promotion. For example, as part of work on planning for major emergencies, the NSMC has approved the joint commissioning of a feasibility study of an all-island Helicopter Emergency Medical Service and this is currently being taken forward. A joint contract is already in place for the disposal of clinical waste.

4.75. Such collaboration is in the best interests of patients North and South, and it is important that the full potential of such co-operation is realised.

Conclusion

4.76. A number of new Local Hospitals will be established to deliver a wide range of services on a local basis. This will go considerably beyond what is currently available from Community Hospitals. They will network with acute hospitals and local primary and community care and provide the backbone of the new hospital service.

4.77. There will be greater differentiation between the roles of the current range of hospitals, concentrating specialised services where necessary, and decentralising other services where possible.

4.78. The nine acute hospitals, including a new acute hospital for Fermanagh/Tyrone, located in, or to the north of Enniskillen as outlined in this paper, represent a viable, robust and sustainable approach to delivering modern and accessible acute services.

4.79. Maternity in-patient services should be provided on nine sites. Midwife-led services should be further developed and two stand-alone midwife-led units will be piloted.

4.80. Opportunities for co-operation between the North and South on a range of healthcare issues should continue and be developed to their full potential.

CHAPTER 5: THE NEED FOR CHANGE IN STRUCTURES

Introduction

5.1. The HPSS is administered by the Department, 4 HSS Boards, 19 Trusts and 5 Special Agencies. There are also 4 Health and Social services Councils. The four Boards were originally set up to deliver the full range of health and social services, under the direction of the Department. With the creation of the internal NHS market in the 1990s, Boards were given responsibility for determining the needs of their population for health and social services. They became commissioners of services, purchasing them from a range of service providers

5.2. The main providers of services were the Trusts, which inherited the responsibility for the delivery of services from the Boards. The newly established Trusts were given a high degree of management autonomy, and competed with each other for contracts covering the delivery of health and social services.

5.3. Recognising the potential for GPs to influence the delivery of hospital services, the then government also established GP Fundholding practices. These were also given commissioning powers and were funded to buy a range of hospital and other services directly from Trusts.

5.4. At present, 19 Trusts and 5 Special Agencies deliver a wide range of hospital, community health and social care services . These consist of 7 Trusts that provide acute hospital services only, 5 Trusts that provide community health and social services only, 6 fully integrated Trusts providing both hospital and community health and social services, and one regional Ambulance Trust. The Special Agencies provide a number of services, including payments to independent practitioners, regional supplies, blood transfusion services, medical physics, guardian ad litem services for children, and health promotion.

5.5. The need for structural reform has been evident since moves to abolish the internal market began. The structures set up to promote the development of an internal market do not reflect the new emphasis on partnership and co-operation. Nor do they readily support the objectives of empowering local communities, targeting social need and removing inequalities, which feature strongly in the Executive's Programme for Government.

5.6. The competitive, internal market, approach has been replaced by a more collaborative approach. GP Fundholding has been abolished, and Local Health and Social Care Groups, (LHSCGs) are in the process of being set up, with the intention of bringing a much more inclusive approach to the identification of local needs and the commissioning of services.

5.7. The current roles of the Department, the 4 HSS Boards, the 19 HSS Trusts, the 5 Special Agencies, and the 4 HSS Councils all need to be reviewed, to determine whether they are appropriate in the new environment of partnership and cooperation signalled in the Executive's Programme for Government.

Relationship with Review of Public Administration

5.8. The Executive has announced its intention to launch a comprehensive review of all aspects of public administration in Northern Ireland. The draft terms of reference which are to be finalised shortly state that the intention is to *"review the existing arrangements for accountability, development, administration and delivery of public services in Northern Ireland, and to bring forward options for reform which are consistent with the arrangements and principles of the Belfast Agreement, within an appropriate framework of political and financial accountability."*

5.9. The review is to be launched in the coming weeks. It is anticipated that there will be a major consultation exercise in the autumn of 2002, with an initial report on progress being produced in spring 2003. It is envisaged that firm conclusions are unlikely to emerge before the end of 2003.

5.10. Clearly there will need to be a two-way inter-relationship between the Review of Public Administration (RPA) and work on structural reform within the HPSS. However, there is no question of this work being unnecessarily delayed because of the RPA. The Executive has agreed that work such as reforming the HPSS should be progressed, but decisions should be taken in a co-ordinated manner, taking account of the emerging principles/criteria from the RPA in determining the final configuration of HPSS structures.

5.11. Following consideration of the responses to the proposals for structural change a further consultation will be required before final decisions can be taken on structural reform.

The Acute Hospitals Review Recommendations on Structures

5.12. The Acute Hospitals Review Group, as part of its consideration of the need for change in the organisation of hospital services, looked at the current organisation of the HPSS and made a number of suggestions for streamlining its structures.

The following paragraphs take account of these suggestions and set out for consultation a number of options for reforming HPSS structures.

5.13. The AHRG proposed that:

- the four HSS Boards should be replaced by a Regional Strategic Health and Social Services Authority outside the Department and by (possibly) three Commissioning Consortia or Partnerships, made up of local health and social care commissioning bodies,
- the 18 HSS Trusts (excluding the Ambulance Trust) should be replaced by 3 integrated Health and Social Care Systems for delivering services; and that
- the four HSS Councils should replaced by a single, statutory consumer body.

5.14. Responses to the initial consultation on the Acute Hospitals Review Group's report showed a general welcome for the proposal for a Strategic Health and Social Services Authority separate from the Department. Mixed views were expressed on the proposal to establish three Health and Social Care Systems.

5.15. Many of those who commented felt that any review should be considered as part of the Executive's proposed Review of Public Administration. However, the Assembly's Health, Social Services and Public Safety Committee felt that a review of the current structures should proceed as quickly as possible, and need not await the forthcoming Review of Public Administration (RPA).

Options for the Reform of HPSS Structures

5.16. The case for reform of HPSS structures is clear, and there is a strong public and professional expectation that Boards will be abolished and that the number of HSS organisations will be reduced significantly. In developing health and social care services for the 21st century, it is essential that the organisational structures support a partnership approach and reinforce the efficient and effective delivery of acute and other vital services. Proposals for reform are set out in the following paragraphs.

Proposals for Reform of Structures

- Creating a single Regional Authority with responsibility for strategic planning, workforce planning and commissioning of regional services
- Replacing the 4 HSS Boards
- Bringing together Local Health and Social Care Groups as commissioning bodies for local health and social services
- Combining HSS Trusts or replacing them altogether
- Replacing the 4 HSS Councils with a single statutory health and social care body

A Single Regional Authority

5.17. It is proposed to create a single Regional Authority, which would have a strong strategic planning and accountability focus. The Authority would carry out key functions such as workforce planning and the commissioning of some regional services, and would have overall responsibility for managing change.

5.18. Following the launch of *"Investing for Health"* in March 2002, the Department is also undertaking a review of the Public Health function. This will be conducted in parallel with, and will take account of, the Review of Public Administration. As many of the functions within Public Health are delivered within the HPSS, this will also have a bearing on any structural reform.

Have your say:

Your views would be welcome on whether or not there should be a single Regional Authority, on the constitution, functions and location of this body, and whether it should be part of the Department or outside it.

Commissioning bodies

5.19. With the disappearance of the four Boards, commissioning would be a major function for individual LHSCGs to handle. In order to share the burden, enhance commissioning power and ensure that there is a consistent approach to commissioning, it is proposed that this role should be exercised by groups of LHSCGs working in partnership. There are a number of ways in which this could be done. A key determinant in setting their number and constitution would be whether they would also deliver a range of community health and social care services.

5.20. Consideration of the options for bringing LHSCGs together will be shaped by the views of the public, staff and other interested parties on whether it is still seen as important to maintain an organisational separation between commissioning and delivery. It will also be influenced by views on whether fully integrated health and social care delivery bodies are the preferred model, in the light of the perceived success or otherwise of the three main types of Trust configuration in operation since the early 1990s.

5.21. Depending on the weight given to these factors, new models for commissioning bodies could include:

- LHSCGs coming together as Commissioning Consortia or Partnerships, with delegated budgets from the regional body, to commission the full range of health and social care services in the light of the assessed needs of their local communities. In this model, given the focus on commissioning, three bodies might be regarded as sufficient for this purpose.

- LHSCGs coming together as fully integrated commissioning and delivery bodies, in which case there would be no further need for Trusts, since responsibility for the delivery of services would pass to these new bodies. Given their responsibility for delivering a wide range of hospital, primary and community health and social services, there would be a case for more than three bodies.

- LHSCGs coming together as Commissioning Consortia or Partnerships, but also with responsibility for the delivery of primary community health and social services, but not acute, services. In this model, there would continue to be a reduced number of acute-only Trusts. Given the range of service delivery responsibilities which these combined LHSCGs would have, there would be a case for more than three bodies.

5.22. Under any of these models, LHSCGs could be constituted either as statutory bodies in their own right, or as operational units of the Regional body.

Options for New Structures: Commissioning[7]

- LHSCGs as commissioning bodies
- LHSCGs as commissioning and delivery bodies
- LGSCGs as commissioning and delivery bodies with the exception of acute services

Have your say:
Your views would be welcome on whether Boards should be abolished, and on the constitution, functions and number of Commissioning bodies.

Trusts

5.23. Depending on the preferred commissioning bodies option, there are a number of different possibilities for Trusts. As a minimum, there should be a significant reduction in the number of HSS Trusts. This should aid effective networking between organisations in the delivery of services, and ensure resources are focused on service users rather than administration. The options include:

- A number of fully integrated Trusts delivering the whole range of hospital, community health and social care services.
- A number of separate acute Trusts and community health and social care Trusts.
- A number of acute only Trusts, with the delivery of community health and social care services being the responsibility of commissioning bodies.
- A number of LHSCGs coming together as fully integrated commissioning and delivery organisations, as described above, which would remove the need for Trusts.

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[7] *The Regional Authority may have some regional commissioning functions*

Options for New Structures: Delivery

These include:
- Fully integrated Trusts
- Separate acute and community Trusts
- Acute only Trusts
- LHSCGs as integrated commissioning and delivery organisations with no Trusts

Have your say:
- **Your views would be welcome on the constitution, functions and number of Trusts, and on whether there should continue to be Trusts.**
- **Any other options for delivery organisations**

A Consumer Body

5.24. It is proposed to match the functions of the 4 HSS Councils with the new structural arrangements. Should there be a new single Regional Authority, we would propose to replace the 4 Councils with a single statutory health and social services consumer body. This should enable the body to reflect the new organisational arrangements in the health and social services, and strengthen the voice of the service user on cross-cutting strategic policy issues. The new body would perform an important role in monitoring the work of the Regional Authority. It would also streamline current arrangements in relation to commissioning research, opinion surveys, and publishing information.

5.25. At the same time, it would be essential to ensure that this body would be constituted to enable it to keep in touch with the views of the public on local issues. There may be a number of ways of achieving this.

5.26. The new LHSCGs have community representation, and this will help to ensure that issues of concern to local communities will be addressed. Nevertheless, should there be single Regional Authority, a strong regional consumer body, in touch with local opinion on local issues, is also required.

Have your say:

- **Your views would be welcome on whether the four HSS Councils should be replaced by a single statutory health and social services consumer body, in the event of a single regional authority.**

- **Your views would be welcome on other ways of achieving consumer representation.**

Conclusion

5.27. It is important that the new structures being proposed will support the close working of all parts of the HPSS, and facilitate the essential linkages which are needed between health and social services and education, housing and other key public services.

5.28. The views of the public, staff and other interested bodies, together with the emerging principles/criteria from the Review of Public Administration, will be pivotal in determining the final shape of these new structures.

5.29. Following consideration of the responses to the proposals for structural change, further consultation will be required before decisions can be taken on final configurations.

CHAPTER 6: EQUALITY

Equality Implications

6.1. Under the statutory Equality obligations (Section 75 of the Northern Ireland Act 1998), due regard must be given to promoting equality of opportunity for the nine statutory equality groups specified in the legislation.

6.2. A preliminary assessment has been carried out of whether the proposals have an adverse or negative impact on people in the nine groups. (A summary of the assessment is at Appendix 2.) This has involved examining travel times using the current configuration of 15 acute hospitals and comparing these to travel times under the 9 site configuration. This was calculated for three possible locations for the new hospital in the Fermanagh/Tyrone area (Enniskillen, Omagh and a green field site half-way between the two at Ederney). The different access times were calculated under three categories, to show the number of wards and the affected population where the difference in travel time either:

(i) decreased, stayed the same or increased by less than 5 minutes,

(ii) increased by between 5 and 30 minutes, or

(iii) increased by more than 30 minutes.

6.3. The composition of each category of wards was then analysed to determine if there were any differences for each equality group living in the three categories of wards.

6.4. Overall the nine site configuration would not appear to have a significant differential impact on the Section 75 equality groups, wherever the new hospital in the Fermanagh/Tyrone area is located. The measures proposed on decentralising services, and those for ameliorating the problems that people face in rural areas, will contribute to promoting equality of opportunity for people in the nine equality groups.

6.5. Everyone cannot live close to an acute hospital but, for people who are geographically isolated, steps can be taken to minimise any risk and ensure that they are not disadvantaged because of where they live.

6.6. Living in a rural area should not prevent people from receiving the high quality care that they need.

Equality

- Effect on travel times of 9 site configuration assessed
- No significant differential impact identified
- Decentralising services and measures for rural areas will promote equality of opportunity

Conclusion

6.7. The proposed 9 acute hospitals should ensure that the vast majority of the population can normally access high quality acute hospital services, including emergency care and maternity services, within 45 minutes and all of the population normally within one hour. Local Hospitals, delivering a range of outpatient, diagnostic, day procedure will network with these hospitals and with local primary and community care. There would not appear to be a significant differential impact on the Section 75 equality groups.

Have Your Say

This Chapter covers a range of important areas. We would like to hear your views on all of the issues raised.

Specific Equality Issues

Can you identify any equality impacts which might occur as a result of these proposals for any of the following groups of people?

- persons of different religious belief,
- persons of different political opinion,
- persons of different racial group,
- persons of different age,
- persons of different marital status,
- persons of different sexual orientation,
- men and women generally,
- persons with a disability and persons without,
- persons with dependants and persons without.

Are there likely to be any specific impacts in terms of tackling deprivation; for example, in relation to the New Targeting Social Need initiative?

CHAPTER 7: RESOURCES AND TIMING

7.1. Funding is critical to the achievement of the vision of modern, high quality services. Resources are limited, and any approach to the development of services must be based on sound planning and careful use of funds. These issues have been carefully considered in the development of these proposals for hospital services which are designed to be implemented over a 9-year period. Bids will have to be made for the necessary resources as part of the normal funding processes.

Capital costs

7.2. To implement the proposals, around £1.2bn of capital at today's prices will be required, over a ten-year development period. The capital funding gap between the capital expected to be available over the period and what is required is estimated as £842m, at today's prices. In seeking to identify sources for the funding required no single solution – be it borrowing, Public Private Partnerships, (PPP) or more traditional public expenditure – is likely to meet our need, and a full range of funding options will be considered.

7.3. The detailed capital assumptions underpinning the Acute Hospitals Review are attached at Appendix 3. The proposals reflect the need for a phased, comprehensive programme of modernisation for the acute sector over the period to 2010/11.

7.4. The proposals recognise that the current pattern of hospital services is not 'fit for purpose', and is ill-equipped to provide the standards of acute hospital care which people are entitled to expect.

7.5. A key ingredient in shaping a modernisation agenda is the need to address vigorously the deficiencies in the infrastructure inherited from Direct Rule. These relate to:

- The failure to maintain the basic estate and equipment inventory;
- The failure to invest in new technology; and
- The cyclical need to replace much of the core acute hospital estate, much of which is 40 years old and older.

Revenue Costs

7.6. The AHRG report indicated that the continuing funding needed to provide the numbers of staff required, will, by 2012, be approximately £165m at today's prices.

Resources, (all at today's prices)

- £1.2bn capital required over 9-year development period
- £842m estimated funding gap
- £165m revenue costs by 2012

7.7. The Department's assessment of future staffing needs mirrors the AHRG view that current services are significantly under-staffed and that this directly impedes the improvements in quality and performance that the hospital service needs to achieve. Its estimate of the projected revenue costs associated with the necessary service developments is consistent with the AHRG figure. These estimates are based on the following:

- A 30% rise in the numbers of Consultant medical staff - this would address current deficiencies and make significant progress towards a consultant provided service, with a greatly reduced dependency on doctors in training to deliver care to service users.

- A 20% rise in the number of qualified nurses - this would address severe workload pressures relating to current nurse staffing levels and enable them to cope with the greater numbers of patients that will be cared for in a modern service. It would also support the increasingly specialised nature of nursing.

- A 25% increase in the number of qualified therapeutic staff - this would provide additional staff to address a growing need for services from speech and language therapists, occupational therapists, physiotherapists etc. These services, which are currently chronically under-staffed, are particularly important in supporting the trend towards shorter stays in hospitals and more community based support.

- The numbers of doctors undergoing GP training will have to be increased, to provide a 25% increase in numbers. This would allow GPs to take on more responsibility for treatments currently provided in hospitals.

- Investment in other staff to support the increases in clinical staff identified above.

Staffing

- 30% increase in consultants
- 20% increase in nurses
- 25% increase in therapeutic staff
- 25% increase in GPs

7.8. These further increases, building on those already in the pipeline, will ensure that there are suitably qualified staff available, to bring services close to self sufficiency in trained staff by the end of the development period.

7.9. To achieve these increases, which are broadly in line with trends elsewhere, the number of people entering pre-registration training across a range of professions will have to be significantly increased.

7.10. There should be no difficulty in attracting students. There is currently a surplus of applicants for available training places. In nursing there are currently four applicants for every place.

7.11. There will be a short-term need to make up the numbers of trained staff, as there will be a time-lag before numbers completing training can be increased. Until the additional professionals are trained and available, the extra posts will be filled by a combination of initiatives. These will include:

- continuing the successful return to practice initiative within nursing and extending this to other health professionals groups;

- taking action to increase the proportion of graduates who are recruited into HPSS when they have completed training;

- developing the role of unqualified staff and enhancing the skills of this group by providing investment in training;

- continuing to draw on the world-wide market for certain professions including nursing and medicine; and

- encouraging more staff to stay on, through initiatives such as investment in professional development and flexible working practices.

7.12. Other initiatives, such as the new consultant contract and the proposals set out in *Agenda For Change*, will also assist in retaining staff within the HPSS.

7.13. A breakdown of projected costs is provided at Appendix 4. These estimates must, of necessity, be revisited in the context of the impact of other policy and service development initiatives, particularly within the community and social services. They will also be affected by service-wide developments, such as compliance with the EU Working Time Directive.

7.14. The arrangements for workforce planning are being strengthened at a regional level. This will provide a mechanism for updating and reviewing the investment required across all HPSS services on a regular basis, as the acute hospital review strategy rolls out over the next 10 years.

Performance

7.15. The hospital service has continued to review its performance, which has improved significantly in recent years. Over the past 10 years, the number of patients treated annually has increased by 38% and, over the same period, there has been a 32% reduction in the number of hospital beds.

7.16. With the changes proposed in the organisation of hospital services, and the provision of additional staff to deliver modern acute care, the performance of the acute sector is expected to further improve, even when account is taken of the predicted growth in the number of very elderly people.

7.17. Once the new pattern of hospital services is established, it should:

- **Eliminate the problem of people waiting for admission** in all hospitals – with all patients transferred to a staffed bed as quickly as possible. All emergency cases will be admitted straight to a bed and no patients will wait more than two hours for admission post-assessment.

- **Bring waiting times for outpatient appointments down** to a maximum of three months, with urgent cases prioritised and seen much more quickly.

- **Reduce waiting times** for elective procedures to a maximum of 3 months.

- **Speed the flow of patients** through the hospital service and ensure that many more will avoid hospital admission altogether.

- **Eliminate delayed discharges** from hospital, with patients moving out of acute hospitals as soon as their acute treatment is successfully concluded.

- **Meet peaks in demand** by flexing available capacity without having to cancel procedures or delay normal work.

Timing

7.18. While the Executive is committed to providing extra resources for hospital services, the extent and speed of that investment will be determined by the Executive, taking full account of available resources and relative priorities across all of its responsibilities.

Conclusion

7.19. This substantial investment is the key to necessary changes. The investment will need to be spread over the next decade to progressively up-grade and improve facilities and to support new clinical practice. This scale of investment is crucial to developing a modern and effective hospital service. It should be seen in the context of a service that has a strong history of increasing productivity and making the best use of resources in the interest of patients.

GLOSSARY OF TERMS

Access Time - estimated time taken by road to the nearest acute hospital based on average speeds on different classes of roads

Acute Services - health care and treatment provided normally in hospitals able to manage planned and emergency procedures.

Acute Trusts - Health and Social Services Trusts which provide acute hospital care only

Clinical and Social Care Governance - a framework within which HPSS organisations are accountable for continuously improving the quality of their services and safeguarding standards of care and treatment

Commissioning - the process of identifying local health and social care needs, drawing up plans to meet those needs, making agreements with service providers to deliver services, and monitoring outcomes

Community Care - health or social care provided outside a hospital

Community Trusts - Trusts which provide community health and social services but not acute hospital services

Consultant-Led Maternity Unit - a maternity in which a consultant is responsible for the clinical care of patients

Consultant-Led Services - services in which a consultant holds responsibility for the clinical management of patients

Day-Case Surgery - surgery which does not require an overnight stay in hospital

Deprivation Indices - indicators used to identify people, groups and areas in greatest social need

Differential Impact - where a particular group would be affected differently by the proposals

Elective Surgery - non-emergency surgery taking place in a hospital and planned in advance

GLOSSARY OF TERMS

Enhanced Local Hospital - a Local Hospital which provides services additional to those normally available in Local Hospitals

Health and Personal Social Services (HPSS) - includes hospital services, community health services, personal social services and general medical services

Health and Social Services Boards - organisations responsible for commissioning health and social services for their resident populations. There are 4 Health and Social Services Boards

Health and Social Services Councils - organisations responsible for representing the views of health and social services users, and for providing an independent oversight of the activities of Health and Social Services Boards

Health and Social Services Trusts - organisations responsible for providing health and social services, and for exercising certain statutory functions on behalf of Health and Social Services Boards

Integrated Trusts - Trusts which provide both hospital and community health and social services

Local Health and Social Care Groups (LHSCGs) - groups of providers of local primary and community services - there will be 15 LHSCGs

Midwife-Led Maternity Unit - maternity units in which the clinical is led by a midwife

Primary Care - care provided by the primary care team, normally led by a general practitioner

Protected Elective Centre - a centre where the surgical treatment is elective only, emergency cases being cared for elsewhere

Providers - organisations which provide health and/or social services

Regional Services - specialist services which are provided from one or two hospital sites for people throughout the region

GLOSSARY OF TERMS

Section 75 Equality Groups - the groups of people specified in Section 75 of the Northern Ireland Act 1998, in respect of whom public authorities, in carrying out their functions, are required to have due regard to the need to promote equality of opportunity and to have regard to the desirability of promoting good relations

Special Agencies - organisations which provide a range of specialised services. There are 5 such agencies: Central Services Agency, Health Promotions Agency, Blood Transfusion Agency, Guardian Ad Litem Agency and the Regional Medical Physics Agency

Sustainability - the viability of a hospital having regard to its ability to treat sufficient numbers of patients to maintain the expert skill base of its clinical teams.

APPENDICES

APPENDIX 1	Location of existing Acute Hospitals
APPENDIX 2	Acute Hospitals Review - Preliminary Assessment of Equality Implications of proposal for 9 Acute Hospitals
APPENDIX 3	Acute Hospitals Review - Projected Capital Costs
APPENDIX 4	Acute Hospitals Review - Projected Additional Revenue, (Staff Costs)
APPENDIX 5	Calculation of Access Times

APPENDIX 1:

Location of Existing Acute Hospitals

APPENDIX 2

ACUTE HOSPITALS REVIEW - PRELIMINARY ASSESSMENT[1] OF EQUALITY IMPLICATIONS OF PROPOSAL FOR 9 ACUTE HOSPITALS

With alternative sites for a new hospital for the Fermanagh/Tyrone area in or to the north of Enniskillen, in Omagh and a green-field site at Ederney

Aim

The aim of this preliminary assessment is to provide a quantitative analysis of whether the proposal to deliver acute services from 9 acute hospital sites is likely to lead to inequalities between people in the designated equality groups. The effect on accessibility among the equality groups is compared with the position under the status quo (15 acute hospital sites). The effect of alternative locations for a new hospital for the Fermanagh/Tyrone area in or to the north of Enniskillen, in Omagh and on a green-field site at Ederney[2], has been assessed.

Methodology

Access times from the centre of each enumeration district (E.D.) to the current 15 acute hospital sites in Northern Ireland were calculated using the software called SMOSS (Simplified Modelling of Spatial Systems). The lowest access time (i.e. time to the nearest hospital) for each E.D. was chosen. These were combined to produce an access time from each electoral ward by calculating an average weighted by the population of each E.D. within the ward[3].

This process was repeated for the 9 acute hospitals site proposal. The times from each electoral ward to the current 15 acute hospital sites were then compared to the times for the 9 acute hospital sites proposed and the difference calculated. The effect on the 566 electoral wards in the North are shown in three categories:

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[1] *A fuller assessment, of which this is a summary, is available on request.*

[2] *Ederney, Co. Fermanagh, is 16 miles from both Enniskillen and Omagh.*

[3] *It should be noted that there could be discrepancies between the individual ward access times predicted by the model and what would be the real travel time. Such discrepancies could arise due to the impact of congestion, road activities and other factors, which it is not possible to take account of in the model. However, the grouping of wards will minimise such discrepancies, as slight overestimates in one ward will be offset by underestimates in another.*

Appendix 2

(a) Number of Wards and population affected (with % of total), where the access time decreased, stayed the same, or increased by less than 5 minutes.

		Decrease, Same or 0-5 min Increase	
		Wards	Population
With new Fermanagh/Tyrone Hospital at:	Enniskillen	428	1,332,211 (78.7%)
	Omagh	437	1,345,671 (79.5%)
	Ederney	414	1,295,563 (76.6%)

(b) Number of Wards and population affected (with % of total), where the access time increased by between 5 and 30 minutes.

		5-30 min Increase	
		Wards	Population
With new Fermanagh/Tyrone Hospital at:	Enniskillen	115	299,743 (17.7%)
	Omagh	108	288,190 (17.0%)
	Ederney	141	365.519 (21.6%)

(c) **Number of Wards and population affected (with % of total), where the access time increased by more than 30 minutes.**

		30+ min Increase	
		Wards	**Population**
With new Fermanagh/Tyrone Hospital at:	**Enniskillen**	23	59,869 (3.5%)
	Omagh	21	57,963 (3.4%)
	Ederney	11	30,742 (1.8%)

The composition of each category of wards (a.- c. above) was then examined to determine if there were differences in the proportion of each equality group living in the wards.

Numerical data was obtained at ward level in respect of the majority of the nine equality groups (or suitable proxies for the groups). Unfortunately, no information was available on sexual orientation and only approximate higher-level data was available in respect of racial group (the Centre for Racial Equality provided some estimates of where the majority of the main racial groups were located in the North - typically at LGD level). Data on political preference was obtained at LGD level from first preference votes cast at the June 2001 Local Government elections (The Electoral Office does not have data in respect of the votes cast for individual electoral wards).

In instances where a direct count of the numbers in a specific group were not available a suitable proxy was used. For example, the aggregate of attendance allowance and incapacity benefit claimants was used as a proxy for those with a disability. However, as there may be issues surrounding take-up of social security benefits, an alternative disability proxy was created based on numbers self-reporting a limiting long-term illness at the 1991 Census of Population (this was the only available data source for a number of the equality groups).

Once the datasets were assembled at ward (or LGD level) it was then possible to map the equality group data to the increase in access times. This then allowed each equality group to be separately analysed in terms of their increase in access times. The proportions of each equality group in the different categories of wards, was then compared.

Conclusion

In general, it can be said that the 9 acute hospitals proposal would not appear to have a significant differential impact on different equality groups wherever the new hospital in the Fermanagh/Tyrone area were to be located. There are some differences between the proportions of the different religious groupings and the different political opinion groupings were it to be located in or to the north of Enniskillen, in Omagh, or in Ederney, but these differences were only apparent in the categories with large increases in access times (c. above). In the case of the rest of the equality groups, there is virtually no difference between the groups in terms of impact.

Appendix 2

Preliminary Assessment of Equality Implications: Summary

	9 Acute Hospitals Proposal with new Fermanagh/Tyrone Hospital at		
(Equality Group)	**Enniskillen**	**Omagh**	**Ederney**
Gender	N	N	N
Age	N	N	N
Marital Status	N	N	N
Disability	N	N	N
Religious Belief	P	P	P
Dependants	N	N	N
Political Opinion	P	P	P
Racial Background	N	N	N

(N) = No differential Impact; (P) = Potential Impact

APPENDIX 3

ACUTE HOSPITALS REVIEW – PROJECTED CAPITAL COSTS

ESTIMATED FINANCIAL PROFILE (PROJECTS)

(based on £814.5m & £135m Backlog Maintenance)

	2002/03	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	Total
Projects*	21.2	52.8	87.5	122.7	137.3	150.0	102.0	89.5	51.5	814.5
Backlog Maintenance	7.0	23.0	15.0	15.0	15.0	15.0	15.0	15.0	15.0	135.0
TOTAL	28.2	75.8	102.5	137.7	152.3	165.0	117.0	104.5	66.5	949.5

ESTIMATED FINANCIAL PROFILE (EQUIPMENT)

	2002/03	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	Total
General eg pendants/monitors	7	15	15	15	15	15	15	15	15	127
Major eg x-ray/labs	3	23	27	6	6	6		6	6	6 89
TOTAL	10	38	42	21	21	21	21	21	21	216

*Costs include works equipment, estimated at a total of £100m

APPENDIX 3

CAPITAL FUNDING GAP

	2002/03	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	Total
Estimated Requirement	38.2	113.8	144.5	158.7	173.3	186.0	138.0	125.5	87.5	1,165.5
Available Provision	36.0	36.0	36.0	36.0	36.0	36.0	36.0	36.0	36.0	324.0
Difference	2.2	77.8	108.5	122.7	137.3	150.0	102.0	89.5	51.5	841.5

Notes:

- The Project Costs are based on current Business Case costs where they have been produced. The costs include equipment provision, estimated at 12.5% of the total cost of each scheme.

- Where Business Cases have not been commenced the costs are based on broad assessments at January 2002 cost estimates.

- The Estimate for the new accute hospital serving Fermanagh/Tyrone does not include utility supplies and road infrastructure works which may be required to enable the new hospital to be built in of the chosen location.

- Locations which are further removed from major conurbations are likely to attract more significant cost implications.

Backlog Maintenance:

- Allowing for these schemes, there would still need to be an allowance made for approximately £15m per annum for Backlog maintenance in light of the time it will take to implement these schemes.

Development in Medical Science & Service Delivery

- The financial projections are based on the current methods of clinical service delivery. Any radical change in clinical technologies could have consequential impact on the estate required to deliver the services and the financial projections.

APPENDIX 4

ACUTE HOSPITALS REVIEW – PROJECTED ADDITIONAL REVENUE (STAFF COSTS)

Profile of Additional Staff Costs over the 10 year period 2002/2012 (in £m)

STAFF GROUP	2002/03	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	Total (£m)
Consultants	2.5	2.5	2.5	2.5	2.5	2.5	2.5	2.5	2.5	2.5	22.5
Nurses	4.5	5.1	6.9	8.3	8.3	8.3	6.9	6.9	6.9	6.9	69.0
GPs	2.9	2.9	2.9	2.9	2.9	2.9	2.9	2.9	2.9	2.9	29.0
Therapists	0.8	0.8	1.6	2.4	2.4	1.6	1.6	1.6	1.6	1.6	16.0
Education	5.5	5.0	5.5	3.5	2.5	2.5	1.0	1.0	1.0	1.0	28.5
Additional Cost Per Annum	**16.2**	**16.3**	**19.4**	**19.6**	**18.6**	**17.8**	**14.9**	**14.9**	**14.9**	**14.9**	**165.0**

APPENDIX 5

CALCULATION OF ACCESS TIMES[1]

Background to the model used

Access times were calculated using a model called Simplified Modelling for Spatial Systems (SMOSS) developed by the Geography Department of Lancaster University. This model was developed to inform a rurality adjustment in the HSS Board capitation formula, and was subsequently adapted for the Northern Ireland Ambulance Service Strategic Review. It was also used to calculate scores for the Access Domain of the Noble Measures of Deprivation. Road conditions and congestion were not taken into account in the model but average speeds on different classes of road have been incorporated. When the model was developed, cross-validation with other available data provided assurance that the model does in fact reflect reality.

The Acute Hospital Review Group (AHRG) used a model developed by consultants for the then Department of the Environment (DOE). Access times produced using the SMOSS model were compared against the times from the DOE model. While access times do differ slightly, the SMOSS model calculates times at a very small geographic area level (enumeration district) and therefore enables the longest access times to be identified. The DOE model uses groups of electoral wards called 'zones' and the longest travel times are not identified as a result. For this reason, the SMOSS model is suitable for producing more detailed analysis to build on the findings produced by the AHRG work.

It should be noted that there could be differences between the individual ward access times predicted by the model and the actual travel time for a specific journey. Such differences could arise due to the impact of congestion, road activities and other factors that could not be taken into account of in the model. However, ward access times provide a reasonable estimate of the average travel time of the ward population taking into account its spatial distribution (i.e. based on average travel times of individual enumeration districts within wards).

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[1] *See Chapter 4, paragraphs 4.55 – 4.56*

APPENDIX 5

Calculation of access times for a new Fermanagh/Tyrone Acute Hospital

A number of steps were taken to derive the figures that appear in the consultation paper and these are described below:

1. The access time from the centre of each enumeration district (E.D.) to the 9 acute hospital sites proposed, was generated by the model. The model was re-run to include each of the 3 suggested sites for the Fermanagh/Tyrone hospital.

2. For each of the 3 configurations of the 9 acute hospitals (based on the 3 suggested locations for the Fermanagh/Tyrone hospital), the minimum access time (i.e. time to the nearest hospital) for each E.D. in the North was selected.

   Example: Table 1 shows access times to each of the 9 hospitals where Omagh is given as the site for the new hospital in Fermanagh/Tyrone. Times are shown from 3 of the EDs in the ward Victoria Bridge, Strabane (there are a total of 9 EDs in this ward). The minimum access time to the nearest hospital for each ED is shown in the last row of the table. For all 3 EDs, the nearest hospital is Tyrone County.

Table 1. Access times from 3 EDs in Victoria Bridge

Hospital	Access times from ED 261401	Access times from ED 261402	Access times from ED 261403
Ulster	116.51	112.57	111.28
Royal	109.52	105.57	104.32
City	109.61	105.64	104.38
Coleraine	80.36	71.57	69.8
Antrim	93.31	89.48	88.22
Craigavon	84.67	80.56	79.01
Daisy Hill	108.19	104.21	102.51
Altnagelvin	48.95	40.9	38.77
Tyrone County	**31.66**	**28.43**	**27.39**
Minimum Access Time	31.66	28.43	27.39

3. These minimum access times at E.D. level are combined to produce an access time from each electoral ward to the nearest hospital, by calculating an average weighted by the population of each E.D. within the ward.

   Example: Table 2 shows the minimum time from each of the 9 EDs in Victoria Bridge to their nearest hospital where for this example Omagh is used as the the suggested location for the new hospital in the Fermanagh/Tyrone area. The populations within each ED are multiplied by the minimum access time for each ED. These 'weighted access times' are summed together for all EDs in the ward and divided by the total population in the ward. This gives a weighted average travel time from the ward of Victoria Bridge to the nearest hospital (i.e. 70117 divided by 2277 equals 30.8 minutes)

Table 2. Access times weighted by population for each ED within Victoria Bridge

ED	Minimum Access Time (minutes)	Population in each ED	Minimum Access Time X Population
261401	31.66	197	6240
261402	28.43	205	5826
261403	27.39	329	9003
261404	25.44	201	5107
261405	28.03	221	6195
261406	32.23	122	3934
261407	28.54	252	7182
261408	32.88	247	8114
261409	36.75	504	18515
Total for ward	Weighted average = 30.8	2277	70117

This weighted average access time for a ward based on the aggregation of ED access times will <u>not</u> be the same as the straight access time from the centre of a ward as a whole to the nearest hospital. This is because the weighted average takes account of variations in access time and population size across the ward and therefore is a more accurate access time.

4. For each of the 3 configurations, the wards with a weighted average access time of over 45 minutes within the Fermanagh/Tyrone area were selected. The population living within each of these wards were summed together to give a figure for the total number of people in the Fermanagh/Tyrone area who had access times of over 45 minutes.

   Example: Table 3 shows the wards in the Fermanagh/Tyrone area only where the access time was over 45 minutes. Therefore the total number of people living in wards where the weighted average access times are over 45 minutes is 24,250.

Table 3. Wards with weighted average access times of over 45 minutes in the Fermanagh/Tyrone area (where the new Fermanagh/Tyrone hospital is in Omagh)

Ward	Local Government District	Population in ward	Average travel time
Derrylin	Fermanagh	2,664	76.1
Belcoo & Garrison	Fermanagh	2,532	67.4
Florence Court & Kinawley	Fermanagh	2,292	62.9
Newtownbutler	Fermanagh	2,261	61.2
Derrygonnelly	Fermanagh	2,365	54.9
Rosslea	Fermanagh	2,335	54.8
Donagh	Fermanagh	2,197	53.9
Belleek & Boa	Fermanagh	2,327	52.6
Boho, Cleenish & Letterbreen	Fermanagh	2,262	52.5
Lisnaskea	Fermanagh	3,016 Total = 24,250*	47.1

* The figures do not add to the total due to rounding.

5. The subset of the population whose travel times were over 50, 55 and 60 minutes were subsequently calculated. In our example (Table 3), 9 wards had an access time of over 50 minutes (21,234 people), 4 wards had an access time of over 55 minutes and 60 minutes (9,749 people). In this case, no wards had access times of between 55 and 60 minutes.

6. In order to assess the input of Southern Hospitals in the analysis, steps 1 – 5 were repeated with the addition of access times generated by the model from each E.D. to relevant hospitals in the South (i.e. Sligo, Cavan and Letterkenny). The final results are shown in Table 4 below.

Table 4. Wards with weighted average access times of over 45 minutes in the Fermanagh/Tyrone area (where the new Fermanagh/Tyrone hospital is in Omagh and hospitals in the South are included)

Ward	Local Government District	Population in ward	Average travel time
Derrygonnelly	Fermanagh	2,364	54.4
Boho, Cleenish & Letterbreen	Fermanagh	2,262 Total = 4,626	49.9

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STATUTORY INSTRUMENTS

2003 No. 431 (N.I. 9)

NORTHERN IRELAND

The Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003

Made - - - - 27th February 2003

Coming into operation in accordance with Article 1

At the Court at Buckingham Palace, the 27th day of February 2003
Present,
The Queen's Most Excellent Majesty in Council

Whereas a draft of this Order in Council has been approved by resolution of each House of Parliament:

Now, therefore, Her Majesty, in exercise of the powers conferred by paragraph 1(1) of the Schedule to the Northern Ireland Act 2000 (c. 1) and of all other powers enabling Her in that behalf, is pleased, by and with the advice of Her Privy Council, to order, and it is hereby ordered, as follows:—

PART I

INTRODUCTORY

Title and commencement

1.—(1) This Order may be cited as the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003.

(2) This Part shall come into operation on the expiration of one month from the day on which this Order is made.

(3) The remaining provisions of this Order shall come into operation on such day or days as the Department may by order appoint.

Interpretation

2.—(1) The Interpretation Act (Northern Ireland) 1954 (c. 33) applies to this Order as it applies to an Act of the Assembly.

(2) In this Order —

“authority”, except in Article 42(1), and “authority foster parent” have the same meanings as in the Children Order;

“Care Tribunal” means the tribunal established under Article 44;

“child” means a person under the age of 18;

“the Children Order” means the Children (Northern Ireland) Order 1995 (NI 2);

“day care setting” means, subject to paragraph (8), a place where persons in need of prescribed services may attend for the purposes of assessment, rehabilitation or counselling but where they are not provided with board or accommodation;

“the Department” means the Department of Health, Social Services and Public Safety;

“domiciliary care agency” means, subject to paragraph (8), an undertaking which consists of or includes arranging the provision of prescribed services in their own homes for persons who by reason of illness, infirmity, disability or family circumstances are unable to provide any such service for themselves without assistance;

“employment agency” and “employment business” have the same meanings as in Part II of the Employment (Miscellaneous Provisions) (Northern Ireland) Order 1981 (NI 20); but no business which is an employment business shall be taken to be an employment agency;

“fostering agency” means, subject to paragraph (8),—

(a) an undertaking (other than an authority) which consists of or includes discharging functions on behalf of an authority in connection with the placing of children with foster parents; or

(b) a voluntary organisation which places children with foster parents under Article 75(1) of the Children Order;

“homeless persons” shall be construed in accordance with Part II of the Housing (Northern Ireland) Order 1988 (NI 23);

“hospital” means, subject to paragraph (8),—

(a) an establishment—

  (i) the main purpose of which is to provide medical or psychiatric treatment for illness or mental disorder or palliative care; or

  (ii) in which (whether or not other services are also provided) any of the listed services are provided;

(b) any other establishment in which treatment or nursing (or both) is provided for persons liable to be detained under the Mental Health (Northern Ireland) Order 1986 (NI 4);

“illness” includes any injury;

“independent clinic” means, subject to paragraph (8), an establishment of a prescribed kind (not being a hospital) in which services are provided by medical practitioners (whether or not any services are also provided for the purposes of the establishment elsewhere), but an establishment in which, or for the purposes of which, services are provided by medical practitioners in pursuance of the Health and Personal Social Services (Northern Ireland) Order 1972 (NI 14) is not an independent clinic;

“independent hospital” means, subject to paragraph (8), a hospital which is not vested in the Department or managed by an HSS trust;

“independent medical agency” means, subject to paragraph (8), an undertaking (not being an independent clinic) which consists of or includes the provision of services by medical practitioners, but if any of the services are provided for the purposes of an independent clinic, or by medical practitioners in pursuance of the Health and Personal Social Services (Northern Ireland) Order 1972, it is not an independent medical agency;

"medical" includes surgical;

"mental disorder" has the same meaning as in the Mental Health (Northern Ireland) Order 1986 (NI 4);

"nursing agency" means, subject to paragraph (8), an employment agency or employment business, being (in either case) a business which consists of or includes supplying, or providing services for the purpose of supplying, registered nurses, registered midwives or registered health visitors;

"nursing home" has the meaning given by Article 11;

"parent", in relation to a child, includes any person who is not a parent of his but who has parental responsibility for him;

"parental responsibility" has the same meaning as in the Children Order;

"personal care" has the meaning given by Article 10(3);

"prescribed" means prescribed by regulations;

"the Regulation and Improvement Authority" means the Northern Ireland Health and Personal Social Services Regulation and Improvement Authority;

"regulations" means regulations made by the Department;

"relative" has the same meaning as in the Children Order;

"residential care home" shall be construed in accordance with Article 10;

"residential family centre" means, subject to paragraph (8), any establishment at which—

(a) accommodation is provided for children and their parents;

(b) the parents' capacity to respond to the children's needs and to safeguard their welfare is monitored or assessed; and

(c) the parents are given such advice, guidance or counselling as is considered necessary,

and in this definition "parent", in relation to a child, includes any person who is looking after the child;

"school" has the meaning assigned to it by Article 2(2) of the Education and Libraries (Northern Ireland) Order 1986 (NI 3);

"service provider" means a person who provides—

(a) services in accordance with agreements under Article 15C of the Health and Personal Social Services (Northern Ireland) Order 1972 (NI 14); or

(b) Part VI services (within the meaning of that Order);

"treatment" includes diagnosis;

"undertaking" includes any business or profession and—

(a) in relation to any public body, includes the exercise of any functions of that body; and

(b) in relation to any other body of persons, whether corporate or unincorporated, includes any of the activities of that body;

"voluntary adoption agency" means a voluntary organisation which is an adoption society within the meaning of the Adoption (Northern Ireland) Order 1987 (NI 22);

"voluntary organisation" has the same meaning as in the Adoption (Northern Ireland) Order 1987 (NI 22).

(3) Other expressions used in the Health and Personal Social Services (Northern Ireland) Order 1972 and this Order have the same meaning in this Order as in that Order unless specifically defined elsewhere in this Order.

(4) References in this Order to a person liable to be detained under the Mental Health (Northern Ireland) Order 1986 (NI 4) do not include a person absent in pursuance of leave granted under Article 15 of that Order.

(5) For the purposes of this Order, the person who carries on—

(a) a fostering agency falling within paragraph (b) of the definition of "fostering agency" in paragraph (2), or

(b) a voluntary adoption agency,

is the voluntary organisation itself.

(6) References in this Order to a person who carries on an establishment or agency include references to a person who carries it on otherwise than for profit.

(7) In the definition of "hospital" in paragraph (2) "listed services" means, subject to paragraph (9),—

(a) a medical treatment under anaesthesia or sedation;

(b) dental treatment under anaesthesia or sedation;

(c) obstetric services and, in connection with childbirth, medical services;

(d) cosmetic surgery;

(e) use of prescribed techniques or prescribed technology.

(8) Regulations may except any description of establishment or undertaking from the following definitions in paragraph (2)—

(a) "day care setting";

(b) "domiciliary care agency";

(c) "fostering agency";

(d) "hospital";

(e) "independent clinic";

(f) "independent hospital";

(g) "independent medical agency";

(h) "nursing agency", and

(i) "residential family centre".

(9) Regulations may modify the definition of "listed services" in paragraph (7).

PART II

NORTHERN IRELAND HEALTH AND PERSONAL SOCIAL SERVICES REGULATION AND IMPROVEMENT AUTHORITY

The Regulation and Improvement Authority

3.—(1) There shall be a body corporate to be known as the Northern Ireland Health and Personal Social Services Regulation and Improvement Authority (in this Order referred to as "the Regulation and Improvement Authority").

(2) Schedule 1 (which makes further provision relating to the Regulation and Improvement Authority) shall have effect.

General duties in relation to provision of services

4.—(1) In this Part "services" means services provided by—

- (a) persons registered under Part III; and
- (b) Health and Social Services Boards, HSS trusts and special agencies.

(2) The Regulation and Improvement Authority shall have the general duties of—

- (a) keeping the Department informed about the provision of services and in particular about their availability and their quality; and
- (b) encouraging improvement in the quality of services.

Advice and information about services

5.—(1) When asked to do so by the Department, the Regulation and Improvement Authority shall give the Department advice, reports or information on such matters relating to the provision of services or the exercise of its functions as may be specified in the Department's request.

(2) The Regulation and Improvement Authority may at any time give advice to the Department on—

- (a) any changes which the Regulation and Improvement Authority thinks should be made in the standards set out in statements under Article 38;
- (b) any other matter connected with the provision of services.

Regulations and directions

6.—(1) The Department may by regulations make provision—

- (a) as to the times at which, the cases in which, the manner in which, the persons in relation to whom or the matters with respect to which, any functions of the Regulation and Improvement Authority are to be exercised;
- (b) as to the matters to be considered or taken into account in connection with the exercise of any functions of the Regulation and Improvement Authority;
- (c) as to the persons to whom any advice, information or reports are to be given or made;
- (d) as to the publication of reports and summaries of reports;
- (e) as to the recovery from prescribed persons of amounts in respect of the expenditure incurred by the Regulation and Improvement Authority in the exercise of its functions;
- (f) for or in connection with the exercise of functions of the Regulation and Improvement Authority in conjunction with the exercise of functions of other persons;
- (g) conferring additional functions on the Regulation and Improvement Authority.

(2) The Department may give directions to the Regulation and Improvement Authority with respect to the exercise of its functions and the Regulation and Improvement Authority must comply with them.

Annual report

7.—(1) As soon as possible after the end of each financial year, the Regulation and Improvement Authority shall make a report to the Department—

(a) on the way in which the Regulation and Improvement Authority has exercised its functions during that year; and

(b) on what it has found in relation to services during that year.

(2) In paragraph (1) "financial year" has the meaning given by paragraph 12(6) of Schedule 1.

PART III

REGULATION OF ESTABLISHMENTS AND AGENCIES

Preliminary

Regulated establishments and agencies: general interpretation

8.—(1) Any reference to a description of establishment in the following provisions of this Order is a reference to—

(a) a children's home;

(b) a day care setting;

(c) an independent clinic;

(d) an independent hospital;

(e) a nursing home;

(f) a residential care home;

(g) a residential family centre; or

(h) such other establishment as may be specified by order under paragraph (3),

and a reference to any establishment is a reference to an establishment of any of those descriptions.

(2) Any reference to a description of agency in the following provisions of this Order is a reference to—

(a) a domiciliary care agency;

(b) a fostering agency;

(c) an independent medical agency;

(d) a nursing agency; or

(e) a voluntary adoption agency; or

(f) such other agency as may be specified by order under paragraph (3),

and a reference to any agency is a reference to an agency of any of those descriptions.

(3) The Department may by order specify establishments for the purposes of paragraph (1) and agencies for the purposes of paragraph (2).

(4) The Department shall not make an order under paragraph (1) or (2) unless a draft of the order has been laid before, and approved by resolution of, the Assembly.

Children's homes

9.—(1) Paragraphs (2) to (5) have effect for the purposes of this Order.

(2) An establishment is a children's home (subject to paragraphs (3) and (4)) if it provides care and accommodation wholly or mainly for children.

(3) An establishment is not a children's home merely because a child is cared for and accommodated there by a parent or relative of his or by a foster parent.

(4) An establishment is not a children's home if it is—

(a) a hospital;

(b) a school;

(c) a residential care home;

(d) a nursing home;

(e) a juvenile justice centre;

(f) used primarily for the accommodation of homeless persons; or

(g) used primarily for or in connection with the provision of cultural, recreational, leisure, social or physical activities,

or if it is of a description excepted by regulations.

(5) For the purposes of this Article a person is a foster parent in relation to a child if—

(a) he is an authority foster parent in relation to the child;

(b) he is a foster parent with whom a child has been placed by a voluntary organisation under Article 75(1)(a) of the Children Order; or

(c) he fosters the child privately.

Residential care homes

10.—(1) For the purposes of this Order, an establishment is a residential care home if it provides or is intended to provide, whether for reward or not, residential accommodation with both board and personal care for persons in need of personal care by reason of—

(a) old age and infirmity;

(b) disablement;

(c) past or present dependence on alcohol or drugs; or

(d) past or present mental disorder.

(2) But an establishment is not a residential care home if it is—

(a) a hospital which is vested in the Department or managed by an HSS trust;

(b) a private hospital as defined in Article 90(2) of the Mental Health (Northern Ireland) Order 1986 (NI 4);

(c) an establishment which is used, or is intended to be used, solely as a nursing home;

(d) a children's home;

(e) a university, or an institution of further education, college of education or school;

or if it is of a description excepted by regulations.

(3) In paragraph (1)—

"disablement", in relation to persons, means that they are substantially and permanently handicapped by illness, congenital deformity, sensory impairment or any other prescribed disability;

"personal care" includes the provision of appropriate assistance in counteracting or alleviating the effects of any of the matters mentioned in paragraph (1)(a) to (d) and, in particular, includes—

(a) action taken to promote rehabilitation;

(b) assistance with physical or social needs; and

(c) counselling,

but does not include any prescribed activity.

Nursing homes

11.—(1) For the purposes of this Order "nursing home" means, subject to paragraph (2), any premises used, or intended to be used, for the reception of, and the provision of nursing for, persons suffering from any illness or infirmity.

(2) The definition in paragraph (1) does not include—

(a) a hospital which is vested in the Department or managed by an HSS trust;

(b) a private hospital as defined in Article 90(2) of the Mental Health (Northern Ireland) Order 1986;

(c) a children's home;

(d) any sanatorium provided at a school or educational establishment and used, or intended to be used, solely by persons at, or members of staff of, that school or establishment or members of their families;

(e) any first aid or treatment room provided at premises to which the Factories Act (Northern Ireland) 1965 (c. 20) or the Office and Shop Premises Act (Northern Ireland) 1966 (c. 26) applies or at a sports ground, show ground or place of public entertainment;

(f) any premises used, or intended to be used, wholly or mainly—

  (i) by a medical practitioner for the purpose of consultations with his patients;

  (ii) by a dental practitioner or chiropodist for the purpose of treating his patients; or

  (iii) for the provision of occupational health facilities;

(g) any premises used, or intended to be used, wholly or mainly as a private dwelling; or

(h) any other premises excepted from that definition by regulations.

Registration

Requirement to register

12.—(1) Any person who carries on or manages an establishment or agency of any description without being registered under this Part in respect of it (as an establishment or, as the case may be, agency of that description) shall be guilty of an offence.

(2) The reference in paragraph (1) to an agency does not include a reference to a voluntary adoption agency.

(3) The Department may by regulations make provision about the keeping of registers by the Regulation and Improvement Authority for the purposes of this Part.

(4) A person guilty of an offence under this Article shall be liable on summary conviction—

(a) if paragraph (5) does not apply, to a fine not exceeding level 5 on the standard scale;

(b) if paragraph (5) applies, to imprisonment for a term not exceeding six months, or to a fine not exceeding level 5 on the standard scale, or to both.

(5) This paragraph applies if—

(a) the person was registered in respect of the establishment or agency at a time before the commission of the offence but the registration was cancelled before the offence was committed; or

(b) the conviction is a second or subsequent conviction of the offence and the earlier conviction, or one of the earlier convictions, was of an offence in relation to an establishment or agency of the same description.

Applications for registration

13.—(1) A person seeking to be registered under this Part shall make an application to the Regulation and Improvement Authority.

(2) The application shall give—

(a) the prescribed information about prescribed matters;

(b) any other information which the Regulation and Improvement Authority reasonably requires the applicant to give,

and shall be accompanied by a fee of the prescribed amount.

(3) Only an individual may apply for registration as the manager of an establishment or agency.

(4) A person who carries on or manages, or wishes to carry on or manage, more than one establishment or agency shall make a separate application in respect of each of them.

Grant or refusal of registration

14.—(1) Paragraphs (2) to (4) apply where an application under Article 13 has been made with respect to an establishment or agency in accordance with the provisions of this Part.

(2) If the Regulation and Improvement Authority is satisfied that—

(a) the requirements of regulations under Article 23; and

(b) the requirements of any other statutory provision which appears to the Regulation and Improvement Authority to be relevant,

are being and will continue to be complied with (so far as applicable) in relation to the establishment or agency, it shall grant the application; otherwise it shall refuse it.

(3) The application may be granted either unconditionally or subject to such conditions as the Regulation and Improvement Authority thinks fit.

(4) On granting the application, the Regulation and Improvement Authority shall issue a certificate of registration to the applicant.

(5) The Regulation and Improvement Authority may at any time—

(a) vary or remove any condition for the time being in force in relation to a person's registration; or

(b) impose an additional condition.

Cancellation of registration

15.—(1) The Regulation and Improvement Authority may at any time cancel the registration of a person in respect of an establishment or agency—

(a) on the ground that that person has been convicted of a relevant offence;

(b) on the ground that any other person has been convicted of such an offence in relation to the establishment or agency;

(c) on the ground that the establishment or agency is being, or has at any time been, carried on otherwise than in accordance with the relevant requirements;

(d) on any ground specified by regulations.

(2) For the purposes of this Article the following are relevant offences—

(a) an offence under this Order or regulations made under it;

(b) an offence under any statutory provision repealed by this Order or regulations made under it;

(c) an offence under the Children Order or regulations made under it;

(d) an offence under the Mental Health (Northern Ireland) Order 1986 (NI 4);

(e) in relation to a voluntary adoption agency, an offence under regulations under Article 10(2) of the Adoption (Northern Ireland) Order 1987 (NI 22) or section 1(3) of the Adoption (Intercountry Aspects) Act (Northern Ireland) 2001 (c. 11).

(3) In this Article "relevant requirements" means—

(a) any requirements or conditions imposed by or under this Part; and

(b) the requirements of any other statutory provision which appear to the Regulation and Improvement Authority to be relevant.

Applications by registered persons

16.—(1) A person registered under this Part may apply to the Regulation and Improvement Authority—

(a) for the variation or removal of any condition relating to the registration; or

(b) for the cancellation of the registration.

(2) But a person may not make an application under paragraph (1)(b)—

(a) if the Regulation and Improvement Authority has given him notice under Article 18(4)(a) of a proposal to cancel the registration, unless the Regulation and Improvement Authority has decided not to take that step; or

(b) if the Regulation and Improvement Authority has given him notice under Article 20(3) of its decision to cancel the registration and the time within which an appeal may be brought has not expired or, if an appeal has been brought, it has not been determined.

(3) An application under paragraph (1) shall be made in such manner and state such particulars as may be prescribed and, if made under paragraph (1)(a), shall be accompanied by a fee of such amount as may be prescribed.

(4) If the Regulation and Improvement Authority decides to grant an application under paragraph (1)(a) it shall serve notice in writing of its decision on the applicant (stating, where applicable, the condition as varied) and issue a new certificate of registration.

(5) If different amounts are prescribed under paragraph (3), the regulations may provide for the Regulation and Improvement Authority to determine which amount is payable in a particular case.

Regulations about registration

17.—(1) Regulations may make provision about the registration of persons under this Part in respect of establishments or agencies, and in particular about—

(a) the making of applications for registration;

(b) the contents of certificates of registration.

(2) Regulations may provide that no application for registration under this Part may be made in respect of a fostering agency, or a voluntary adoption agency, which is an unincorporated body.

(3) Regulations may also require persons registered under this Part to pay to the Regulation and Improvement Authority an annual fee of such amount, and at such a time, as may be prescribed.

(4) A fee payable by virtue of this Article may, without prejudice to any other method of recovery, be recovered summarily as a civil debt.

Registration procedure

Notice of proposals

18.—(1) Paragraphs (2) and (3) apply where a person applies for registration in respect of an establishment or agency.

(2) If the Regulation and Improvement Authority proposes to grant the application subject to any conditions which have not been agreed in writing between it and the applicant, it shall give the applicant written notice of its proposal and of the conditions subject to which it proposes to grant his application.

(3) The Regulation and Improvement Authority shall give the applicant notice of a proposal to refuse the application.

(4) Except where it makes an application under Article 21, the Regulation and Improvement Authority shall give any person registered in respect of an establishment or agency notice of a proposal—

- (a) to cancel the registration (otherwise than in accordance with an application under Article 16(1)(b));
- (b) to vary or remove (otherwise than in accordance with an application under Article 16(1)(a)) any condition for the time being in force in relation to the registration; or
- (c) to impose any additional condition in relation to the registration.

(5) The Regulation and Improvement Authority shall give the applicant notice of a proposal to refuse an application under Article 16(1)(a).

(6) A notice under this Article shall give the Regulation and Improvement Authority's reasons for its proposal.

Right to make representations

19.—(1) A notice under Article 18 shall state that within 28 days of service of the notice any person on whom it is served may make written representations to the Regulation and Improvement Authority concerning any matter which that person wishes to dispute.

(2) Where a notice has been served under Article 18, the Regulation and Improvement Authority shall not determine any matter to which the notice relates until either—

- (a) any person on whom the notice was served has made written representations to it concerning the matter;
- (b) any such person has notified the Regulation and Improvement Authority in writing that he does not intend to make representations; or
- (c) the period during which any such person could have made representations has elapsed.

Notice of decisions

20.—(1) If the Regulation and Improvement Authority decides to grant an application for registration in respect of an establishment or agency unconditionally, or subject only to conditions which have been agreed in writing between it and the applicant, it shall give the applicant written notice of its decision.

(2) A notice under paragraph (1) shall state the agreed conditions.

(3) If the Regulation and Improvement Authority decides to adopt a proposal under Article 18, it shall serve notice in writing of its decision on any person on whom it was required to serve notice of the proposal.

(4) A notice under paragraph (3) shall—

- (a) explain the right of appeal conferred by Article 22;
- (b) in the case of a decision to adopt a proposal under Article 18(2), state the conditions subject to which the application is granted; and
- (c) in the case of a decision to adopt a proposal under Article 18(4)(b) or (c), state the condition as varied, the condition which is removed or (as the case may be) the additional condition imposed.

(5) Subject to paragraph (6), a decision of the Regulation and Improvement Authority to adopt a proposal under Article 18(2) or (4) shall not take effect—

- (a) if no appeal is brought, until the expiration of the period of 28 days referred to in Article 22(2); and
- (b) if an appeal is brought, until it is determined or abandoned.

(6) Where, in the case of a decision to adopt a proposal under Article 18(2), the applicant notifies the Regulation and Improvement Authority in writing before the expiration of the period mentioned in paragraph (5)(a) that he does not intend to appeal, the decision shall take effect when the notice is served.

Urgent procedure for cancellation etc.

21.—(1) If—

- (a) the Regulation and Improvement Authority applies to a justice of the peace for an order—
  - (i) cancelling the registration of a person in respect of an establishment or agency;
  - (ii) varying or removing any condition for the time being in force by virtue of this Part; or
  - (iii) imposing an additional condition; and
- (b) it appears to the justice that, unless the order is made, there will be a serious risk to a person's life, health or well-being,

the justice may make the order, and the cancellation, variation, removal or imposition shall have effect from the time when the order is made.

(2) An application under paragraph (1) may, if the justice thinks fit, be made without notice.

(3) As soon as practicable after the making of an application under this Article, the Regulation and Improvement Authority shall notify the Department and the appropriate authority of the making of the application.

(4) An order under paragraph (1) shall be in writing.

(5) Where such an order is made, the Regulation and Improvement Authority shall, as soon as practicable after the making of the order, serve on the person registered in respect of the establishment or agency—

(a) a copy of the order; and

(b) notice of the right of appeal conferred by Article 22.

Appeals to the Care Tribunal

22.—(1) An appeal against—

(a) a decision of the Regulation and Improvement Authority under this Part; or

(b) an order made by a justice of the peace under Article 21,

shall lie to the Care Tribunal.

(2) No appeal against a decision or order may be brought by a person more than 28 days after service on him of notice of the decision or order.

(3) On an appeal against a decision of the Regulation and Improvement Authority the Tribunal may confirm the decision or direct that it shall not have effect.

(4) On an appeal against an order made by a justice of the peace the Tribunal may confirm the order or direct that it shall cease to have effect.

(5) The Tribunal shall also have power on an appeal against a decision or order—

(a) to vary any condition for the time being in force in respect of the establishment or agency to which the appeal relates;

(b) to direct that any such condition shall cease to have effect; or

(c) to direct that any such condition as it thinks fit shall have effect in respect of the establishment or agency.

Regulations

Regulations relating to establishments and agencies

23.—(1) Regulations may impose in relation to establishments and agencies any requirements which the Department thinks fit for the purposes of this Part and may in particular make any provision such as is mentioned in paragraph (2) or (7).

(2) Regulations may—

(a) make provision as to the persons who are fit to carry on or manage an establishment or agency;

(b) make provision as to the persons who are fit to work at an establishment or for the purposes of an agency;

(c) make provision as to the fitness of premises to be used as an establishment or for the purposes of an agency;

(d) make provision for securing the welfare of persons accommodated in an establishment or provided with services by an establishment, an independent medical agency or a domiciliary care agency;

(e) make provision for securing the welfare of children placed, under Article 27(2)(a) of the Children Order, by a fostering agency;

(f) make provision as to the management and control of the operations of an establishment or agency;

(g) make provision as to the numbers of persons, or persons of any particular type, working at an establishment or for the purposes of an agency;

(h) make provision as to the management and training of such persons;

(i) impose requirements as to the financial position of an establishment or agency;

(j) make provision requiring the person carrying on an establishment or agency to appoint a manager in prescribed circumstances.

(3) Regulations under paragraph (2)(a) may, in particular, make provision for prohibiting persons from managing an establishment or agency unless they are registered in, or in a particular part of, any register specified in the regulations for the purposes of this paragraph .

(4) Regulations under paragraph (2)(b) may, in particular, make provision for prohibiting persons from working in such positions as may be prescribed at an establishment, or for the purposes of an agency, unless they are registered in, or in a particular part of, any register specified in the regulations for the purposes of this subsection.

(5) Regulations under sub-paragraph (d) of paragraph (2) may, in particular, make provision—

(a) as to the promotion and protection of the health of persons such as are mentioned in that sub-paragraph;

(b) as to the control and restraint of adults accommodated in, or provided with services by, an establishment;

(c) as to the control, restraint and discipline of children accommodated in, or provided with services by, an establishment.

(6) Regulations under sub-paragraph (e) of paragraph (2) may, in particular, make provision—

(a) as to the promotion and protection of the health of children such as are mentioned in that sub-paragraph;

(b) as to the control, restraint and discipline of such children.

(7) Regulations may make provision as to the conduct of establishments and agencies, and such regulations may in particular—

(a) make provision as to the facilities and services to be provided in establishments and by agencies;

(b) make provision as to the keeping of accounts;

(c) make provision as to the keeping of documents and records;

(d) make provision as to the notification of incidents occurring in establishments or in premises used for the purposes of agencies;

(e) make provision as to the giving of notice by the person carrying on an establishment or agency of periods during which he or (if he does not manage it himself) the manager proposes to be absent from the establishment or agency, and specify the information to be supplied in such a notice;

(f) provide for the making of adequate arrangements for the running of an establishment or agency during a period when the manager is absent from it;

(g) make provision as to the giving of notice by a person registered in respect of an establishment or agency of any intended change in the identity of the manager or the person carrying it on;

(h) make provision as to the giving of notice by a person registered in respect of an establishment or agency which is carried on by a body corporate of changes in the ownership of the body or the identity of its officers;

(i) make provision requiring the payment of a fee of such amount as may be prescribed in respect of any notification required to be made by virtue of sub-paragraph (h);

(j) make provision requiring arrangements to be made by the person who carries on, or manages, an establishment or agency for dealing with complaints made by or on behalf of those seeking, or receiving, any of the services provided in the establishment or by the agency and requiring that person to take steps for publicising the arrangements;

(k) make provision requiring arrangements to be made by the person who carries on, or manages, an independent hospital, independent clinic or independent medical agency for securing that any medical or psychiatric treatment, or listed services, provided in or for the purposes of the establishment or (as the case may be) for the purposes of the agency are of appropriate quality and meet appropriate standards;

(l) make provision requiring arrangements to be made by the person who carries on, or manages, a residential care home or nursing home for securing that any nursing provided by the home is of appropriate quality and meets appropriate standards.

(8) Before making regulations under this Article, except regulations which amend other regulations made under this Article and do not, in the opinion of the Department, effect any substantial change in the provision made by those regulations, the Department shall consult any person it considers appropriate.

(9) References in this Article to agencies do not include references to voluntary adoption agencies.

(10) In paragraph (7)(k), “listed services” has the meaning given in Article 2(7).

Offences

Failure to comply with conditions

24. If a person registered in respect of an establishment or agency fails, without reasonable excuse, to comply with any condition for the time being in force by virtue of this Part in respect of the establishment or agency, he shall be guilty of an offence and liable on summary conviction to a fine not exceeding level 5 on the standard scale.

Contravention of regulations

25.—(1) Regulations under this Part may provide that a contravention of any specified provision of the regulations shall be an offence.

(2) A person guilty of an offence under the regulations shall be liable on summary conviction to a fine not exceeding level 4 on the standard scale.

False descriptions of establishments and agencies

26.—(1) A person who, with intent to deceive any person—

(a) applies any name to premises; or

(b) in any way describes such premises or holds such premises out,

so as to indicate, or reasonably be understood to indicate, that the premises are an establishment, or an agency, of a particular description shall be liable on summary conviction to a fine not exceeding level 5 on the standard scale unless registration has been effected under this Part in respect of the premises as an establishment or agency of that description.

(2) References to premises in paragraph (1) shall be taken to include references to an undertaking or organisation.

(3) No person shall, with intent to deceive any person, in any way describe or hold out an establishment or agency as able to provide any service or do any thing the provision or doing of which would contravene a condition in force by virtue of this Part in respect of the establishment or agency.

(4) A person who contravenes paragraph (3) shall be guilty of an offence and liable on summary conviction to a fine not exceeding level 5 on the standard scale.

False statements in applications

27.—(1) Any person who, in an application for registration under this Part or for the variation of any condition in force in relation to his registration, knowingly makes a statement which is false or misleading in a material respect shall be guilty of an offence.

(2) A person guilty of an offence under this Article shall be liable on summary conviction to a fine not exceeding level 4 on the standard scale.

Failure to display certificate of registration

28.—(1) A certificate of registration issued under this Part in respect of any establishment or agency shall be kept affixed in a conspicuous place in the establishment or at the agency.

(2) If default is made in complying with paragraph (1), any person registered in respect of the establishment or agency shall be guilty of an offence and liable on summary conviction to a fine not exceeding level 2 on the standard scale.

Proceedings for offences

29.—(1) Proceedings in respect of an offence under this Part or regulations made under it shall not, without the consent of the Director of Public Prosecutions for Northern Ireland, be taken by any person other than the Regulation and Improvement Authority.

(2) Proceedings for an offence under this Part or regulations made under it may be brought within a period of six months from the date on which evidence sufficient in the opinion of the prosecution to warrant the proceedings came to its knowledge; but no such proceedings shall be brought by virtue of this paragraph more than three years after the commission of the offence.

(3) Until the commencement of section 41(2) of the Justice (Northern Ireland) Act 2002 (c. 26) the reference in paragraph (1) to the Director of Public Prosecutions for Northern Ireland shall be construed as a reference to the Attorney General for Northern Ireland.

Supplementary

Annual returns

30.—(1) Regulations may require the person carrying on an establishment or agency to make an annual return to the Regulation and Improvement Authority.

(2) Provision may be made by the regulations as to the contents of the return and the period in respect of which and date by which it is to be made.

Liquidators etc.

31.—(1) Regulations may—

(a) require any person to whom this Article applies to give notice of his appointment to the Regulation and Improvement Authority;

(b) require any person to whom this Article applies to appoint a person to manage the establishment or agency in question.

(2) This Article applies to any person appointed as—

(a) a receiver or manager of the property of a relevant company;

(b) the liquidator or provisional liquidator of a relevant company; or

(c) the trustee in bankruptcy of a relevant individual.

(3) In this Article—

"company" includes a partnership;

"relevant company" means a company which is registered under this Part in respect of an establishment or agency; and

"relevant individual" means an individual who is registered under this Part in respect of an establishment or agency.

Death of registered person

32.—(1) Regulations may—

(a) provide for the provisions of this Part to apply with prescribed modifications in cases where a person who was the only person registered under this Part in respect of an establishment or agency has died;

(b) require the personal representatives of a deceased person who was registered in respect of an establishment or agency to notify the Regulation and Improvement Authority of his death.

(2) Regulations under paragraph (1)(a) may in particular—

(a) provide for the establishment or agency to be carried on for a prescribed period by a person who is not registered in respect of it; and

(b) include provision for the prescribed period to be extended by such further period as the Regulation and Improvement Authority may allow.

Provision of copies of register

33.—(1) Subject to paragraph (3), the Regulation and Improvement Authority shall secure that copies of any register kept for the purposes of this Part are available at its offices for inspection at all reasonable times by any person.

(2) Subject to paragraphs (3) and (4), any person who asks the Regulation and Improvement Authority for a copy of, or of an extract from, any register kept for the purposes of this Part shall be entitled to have one.

(3) Regulations may provide that paragraphs (1) and (2) shall not apply—

(a) in such circumstances as may be prescribed; or

(b) to such parts of a register as may be prescribed.

(4) A fee determined by the Regulation and Improvement Authority shall be payable for the copy except—

(a) in prescribed circumstances;

(b) in any other case where the Regulation and Improvement Authority considers it appropriate to provide the copy free of charge.

PART IV

QUALITY OF HEALTH AND PERSONAL SOCIAL SERVICES

Duty of quality

34.—(1) Each Health and Social Services Board and each HSS trust shall put and keep in place arrangements for the purpose of monitoring and improving the quality of—

(a) the health and personal social services which it provides to individuals; and

(b) the environment in which it provides them.

(2) The Department may by regulations extend the duty in this Article to any special agency specified in the regulations.

Role of the Regulation and Improvement Authority

35.—(1) The Regulation and Improvement Authority shall have the following functions—

(a) the function of conducting reviews of, and making reports on, arrangements by statutory bodies for the purpose of monitoring and improving the quality of the health and personal social services for which they have responsibility;

(b) the function of carrying out investigations into, and making reports on, the management, provision or quality of the health and personal social services for which statutory bodies have responsibility;

(c) the function of conducting reviews of, and making reports on, the management, provision or quality of, or access to or availability of, particular types of health and personal social services for which statutory bodies or service providers have responsibility;

(d) the function of carrying out inspections of statutory bodies and service providers, and persons who provide or are to provide services for which such bodies or providers have responsibility, and making reports on the inspections; and

(e) such functions as may be prescribed relating to the management, provision or quality of, or access to or availability of, services for which prescribed statutory bodies or prescribed service providers have responsibility.

(2) The inspections referred to in paragraph (1)(d) are to be carried out only in connection with the function referred to in paragraph (1)(c).

(3) If after carrying out—

(a) a review under paragraph (1)(a);

(b) an investigation under paragraph (1)(b);

(c) any function equivalent to one referred to in sub-paragraph (a) or (b) prescribed under paragraph (1)(e); or

(d) an inspection under paragraph (1)(d),

the Regulation and Improvement Authority is of the view referred to in paragraph (4) as to a body, service provider or other person reviewed, investigated or inspected (taking account, if appropriate, of any other relevant information the Authority may have), the Regulation and Improvement Authority must make a report of its view to the Department.

(4) The view referred to is that—

(a) the health and personal social services for which the body or service provider in question has responsibility are of unacceptably poor quality (whether generally or in particular areas); or

(b) there are significant failings in the way the body, service provider or other person is being run (including, where the service provider or other person is an individual, the way his practice is being run).

(5) In its report, the Regulation and Improvement Authority may recommend that the Department take special measures in relation to the body or service provider in question with a view to improving the health and personal social services for which it is responsible or the way the body, service provider or other person (or, as mentioned in paragraph (4)(b), his practice), is being run.

(6) The report must give the Regulation and Improvement Authority's reasons for its view, and for any recommendation under paragraph (5).

(7) For the purposes of this Article a person has responsibility for health and personal social services—

(a) if he provides or is to provide those services to individuals; or

(b) if another person provides or is to provide those services to individuals—

  (i) at his direction,

  (ii) on his behalf, or

  (iii) in accordance with an agreement or arrangements made by him with that other person.

(8) References in paragraph (7) to the provision of health and personal social services include references to the provision of those services jointly with another person.

(9) In this Article—

"statutory body" means a Health and Social Services Board, an HSS trust or a special agency;

"statutory function" means a function conferred by or under any statutory provision.

PART V

BOARDS AND HSS TRUSTS – ADOPTION, FOSTERING AND CHILDREN UNDER 12

Provision of information

36.—(1) Each Health and Social Services Board and each HSS trust shall give the Regulation and Improvement Authority—

(a) prescribed information about prescribed matters relating to the Board's or trust's Part V functions; and

(b) any other information which the Regulation and Improvement Authority reasonably requires the Board or trust to give it relating to those functions.

(2) In this Article and Article 37 "Part V functions" means—

(a) functions as an adoption agency within the meaning of the Adoption (Northern Ireland) Order 1987 (NI 22);

(b) functions relating to children placed with authority foster parents under Article 27(2)(a) of the Children Order;

(c) functions under Part XI of the Children Order (child minding and day care for young children).

Annual returns

37.—(1) Regulations may require Health and Social Services Boards and HSS trusts to make an annual return to the Regulation and Improvement Authority about their Part V functions.

(2) Provision may be made by the regulations as to the contents of the return and the period in respect of which and date by which it is to be made.

PART VI

MISCELLANEOUS

Statements of minimum standards

38.—(1) The Department may prepare and publish statements of minimum standards.

(2) The Department shall keep the standards set out in the statements under review and may publish amended statements whenever it considers it appropriate to do so.

(3) Before issuing a statement, or an amended statement which in the opinion of the Department effects a substantial change in the standards, the Department shall consult any persons it considers appropriate.

(4) The standards shall be taken into account—

(a) in the making of any decision by the Regulation and Improvement Authority under Part III;

(b) in any proceedings for the making of an order under Article 21;

(c) in any proceedings on an appeal against such a decision or order; and

(d) in any proceedings for an offence under regulations under Part III.

Improvement notices

39.—(1) The Regulation and Improvement Authority may serve a notice (an "improvement notice") on a person registered under Part III or on a Health and Social Services Board, HSS trust or special agency if the Authority believes that that person, Board, trust or agency is failing to comply with any statement of minimum standards under Article 38.

(2) An improvement notice shall specify—

(a) in what respect there is a failure to comply with a statement of minimum standards under Article 38; and

(b) what improvements the Regulation and Improvement Authority considers necessary.

Power to require information from establishments and agencies and power of entry and inspection

40.—(1) The Regulation and Improvement Authority may at any time require a person who carries on or manages an establishment or agency to provide it with any information relating to the establishment or agency which the Regulation and Improvement Authority considers it necessary or expedient to have for the purposes of its functions.

(2) A person authorised by the Regulation and Improvement Authority may at any time enter and inspect premises which are used, or which he has reasonable cause to believe to be used, as an establishment or for the purposes of an agency.

(3) A person authorised by virtue of this Article to enter and inspect premises may—

(a) make any examination into the state and management of the premises and treatment of patients or persons accommodated or cared for there which he thinks appropriate;

(b) inspect and take copies of any documents or records required to be kept in accordance with regulations under Part III, Article 10 of the Adoption (Northern Ireland) Order 1987 (NI 22), Article 27(2)(a) or 75(2) of the Children (Northern Ireland) Order 1995 (NI 2) or section 1(3) of the Adoption (Intercountry Aspects) Act (Northern Ireland) 2001 (c. 11);

(c) interview in private the manager or the person carrying on the establishment or agency;

(d) interview in private any person employed there;

(e) interview in private any patient or person accommodated or cared for there who consents to be interviewed.

(4) The powers under paragraph (3)(b) include—

(a) power to require the manager or the person carrying on the establishment or agency to produce any documents or records, wherever kept, for inspection on the premises; and

(b) in relation to records which are kept by means of a computer, power to require the records to be produced in a form in which they are legible and can be taken away.

(5) Paragraph (6) applies where the premises in question are used as an establishment and the person so authorised—

(a) is a medical practitioner or registered nurse; and

(b) has reasonable cause to believe that a patient or person accommodated or cared for there is not receiving proper care.

(6) The person so authorised may, with the consent of the person mentioned in paragraph (5)(b), examine him in private and inspect any records relating to his care or treatment in the establishment.

The powers conferred by this paragraph may be exercised in relation to a person who is incapable of giving consent without that person's consent.

(7) The Department may by regulations require the Regulation and Improvement Authority to arrange for premises which are used as an establishment or for the purposes of an agency to be inspected on such occasions or at such intervals as may be prescribed.

Power to require information from inspections relating to Boards and HSS trusts, etc. and powers of entry and inspection

41.—(1) The Regulation and Improvement Authority may at any time require a Health and Social Services Board, HSS trust or special agency (in this Article referred to as an "HSS body") or service provider to provide it with any information which the Regulation and Improvement Authority considers it necessary or expedient to have for the purposes of its functions.

(2) Subject to paragraph (3), a person authorised by the Regulation and Improvement Authority may at any time—

(a) enter and inspect premises which are used by an HSS body or service provider; and

(b) inspect and take copies of any documents or records.

(3) If the person is authorised only for the purposes of functions under Article 35(1)(a), (c) or (e) (reviews etc.), he shall enter the premises only—

(a) after giving reasonable notice to the HSS body or service provider;

(b) at a reasonable time; and

(c) if the premises are wholly or partly used as residential accommodation by persons employed by the HSS body or service provider, after obtaining the consent of those persons.

(4) A person authorised by virtue of this Article to enter and inspect premises may—

(a) make any examination into the state and management of the premises and treatment of patients or persons accommodated or cared for there which he thinks appropriate;

(b) interview in private any person employed by an HSS body or service provider;

(c) interview in private any person employed to provide services to an HSS body;

(d) interview in private any patient or person accommodated or cared for there who consents to be interviewed.

(5) The powers under paragraph (2)(b) include—

(a) power to require an HSS body or service provider to produce any documents or records, wherever kept, for inspection on the premises; and

(b) in relation to records which are kept by means of a computer, power to require the records to be produced in a form in which they are legible and can be taken away.

(6) Paragraph (7) applies where a person authorised by the Regulation and Improvement Authority—

(a) is a medical practitioner or registered nurse; and

(b) has reasonable cause to believe that a patient or person accommodated or cared for on premises used by an HSS body or service provider is not receiving proper care or treatment.

(7) The person so authorised may, with the consent of the person mentioned in paragraph (6)(b), examine him in private and inspect any records relating to his care or treatment there.

The powers conferred by this paragraph may be exercised in relation to a person who is incapable of giving consent without that person's consent.

(8) The Department may by regulations require the Regulation and Improvement Authority to arrange for premises which are used by an HSS body or service provider to be inspected on such occasions or at such intervals as may be prescribed.

Inspections: provisions supplementary to Articles 40 and 41

42.—(1) A person who proposes to exercise any power of entry or inspection conferred by Article 40 or 41 shall if so required produce some duly authenticated document showing his authority to exercise the power.

(2) Any person who—

(a) intentionally obstructs the exercise of any power conferred by Article 40 or 41 or this Article; or

(b) fails without a reasonable excuse to comply with any requirement under Article 40 or 41 or this Article,

shall be guilty of an offence and liable on summary conviction to a fine not exceeding level 4 on the standard scale.

(3) A person authorised by virtue of Article 40 or 41 to enter and inspect any premises may seize and remove any document or other material or thing found there which he has reasonable grounds to believe may be evidence of a failure to comply with any condition or requirement imposed by or under this Order.

(4) A person so authorised—

(a) may require any person to afford him such facilities and assistance with respect to matters within the person's control as are necessary to enable him to exercise his powers under Article 40 or 41 or this Article;

(b) may take such measurements and photographs and make such recordings as he considers necessary to enable him to exercise those powers.

(5) A person authorised by virtue of Article 40 or 41 to inspect any records shall be entitled to have access to, and to check the operation of, any computer and any associated apparatus which is or has been in use in connection with the records in question.

(6) The references in Article 40 to the person carrying on the establishment or agency include, in the case of an establishment or agency which is carried on by a company, a reference to any director, manager, secretary or other similar officer of the company.

(7) Where any premises which are used as an establishment or for the purposes of an agency have been inspected under Article 40 the Regulation and Improvement Authority—

(a) shall prepare a report on the matters inspected; and

(b) shall without delay send a copy of the report to each person who is registered in respect of the establishment or agency.

Restrictions on disclosure of information under Article 40 or 41

43.—(1) Subject to subsection (2), a person shall not be required under Article 40 or 41 to provide confidential information which relates to and identifies a living individual unless—

(a) the information is disclosed in a form in which the identity of the individual cannot be ascertained;

(b) the individual consents to the information being disclosed; or

(c) the individual cannot be traced despite the taking of all reasonable steps.

(2) A person may be required to provide confidential information which relates to and identifies a living individual if—

(a) it is not practicable to disclose the information in a form in which the identity of the individual cannot be ascertained;

(b) the Regulation and Improvement Authority considers that there is a serious risk to the health or safety of any person; and

(c) having regard to that risk and the urgency of the exercise of those functions, the Regulation and Improvement Authority considers that the information should be disclosed without the consent of the individual.

(3) A person shall not be required under Article 40 or 41 to provide information the disclosure of which is prohibited under another statutory provision unless—

(a) the prohibition on the disclosure of information operates by reason of the fact that the information is capable of identifying an individual; and

(b) the information in question is in a form in which the identity of the individual cannot be ascertained.

(4) In a case where—

(a) the disclosure of information is prohibited under this Article; and

(b) the prohibition operates by reason of the fact that the information is capable of identifying an individual,

the Regulation and Improvement Authority or a person authorised by it under Article 40 or 41 may require the person holding the information to put the information in a form in which the identity of the individual concerned cannot be identified, in order that the information may be disclosed.

(5) In this Article "confidential information" means information which is held subject to a duty of confidence, and includes information contained in an accessible record within the meaning of section 68 of the Data Protection Act 1998 (c. 29).

The Care Tribunal

44.—(1) There shall be a tribunal ("the Care Tribunal") which shall exercise the jurisdiction conferred on it by this Order or any other statutory provision.

(2) The Department may by regulations make provision about the proceedings of the Care Tribunal.

(3) The regulations may, in particular, include provision—

- (a) as to the manner in which appeals are to be instituted or applications for determinations are to be made;
- (b) as to the period within which appeals are to be instituted;
- (c) as to the circumstances in which applications for leave may be made;
- (d) for enabling any functions which relate to applications for leave or other matters preliminary or incidental to an appeal or determination to be performed by the chairman;
- (e) for the holding of hearings in private in prescribed circumstances;
- (f) for imposing reporting restrictions in prescribed circumstances;
- (g) as to the persons who may appear on behalf of the parties;
- (h) for granting any person such discovery or inspection of documents or right to further particulars as might be granted by a county court;
- (i) for obtaining a medical report in a case where the decision appealed against was made on medical grounds;
- (j) for requiring persons to attend to give evidence and produce documents;
- (k) for authorising the administration of oaths to witnesses;
- (l) for the determination of appeals or issues or applications for leave without a hearing in prescribed circumstances;
- (m) as to the withdrawal of appeals or applications for determinations;
- (n) for the award of costs;
- (o) for taxing or otherwise settling any such costs (and, in particular, for enabling such costs to be taxed in the county court);
- (p) for the recording and proof of decisions and orders of the Care Tribunal;
- (q) for enabling the Care Tribunal to review its decisions, or revoke or vary its orders, in such circumstances as may be determined in accordance with the regulations; and
- (r) for notification of the result of an appeal or determination to be given to such persons as may be prescribed.

(4) Part I of the Arbitration Act 1996 (c. 23) shall not apply to any proceedings before the Care Tribunal but regulations may make provision corresponding to any provision of that Act.

(5) Any person who without reasonable excuse fails to comply with—

- (a) any requirement imposed by the regulations by virtue of paragraph (3)(f);
- (b) any requirement in respect of the discovery or inspection of documents imposed by the regulations by virtue of paragraph (3)(h); or
- (c) any requirement imposed by the regulations by virtue of paragraph (3)(j),

is liable on summary conviction to a fine not exceeding level 3 on the standard scale.

(6) An appeal shall lie to the High Court on a point of law from a decision of the Care Tribunal.

(7) Schedule 2 shall have effect with respect to the Care Tribunal.

Arrangements for provision of accommodation outside Northern Ireland

45. In Article 36 of the Health and Personal Social Services (Northern Ireland) Order 1972 (NI 14) (arrangements under Article 15 for provision of accommodation), for paragraphs (1) and (2) there shall be substituted the following paragraphs—

> "(1) Subject to paragraph (2), arrangements must not be made under Article 15 for the provision of accommodation together with nursing or personal care for persons such as are mentioned in Article 10(1) of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003 (residential care homes) unless—
>
> (a) the accommodation is to be provided, under the arrangements, in a residential care home or nursing home (within the meaning of that Order); and
>
> (b) a person carrying on or managing the home is registered in respect of it under that Order.
>
> (2) The Department may by regulations make provision for or in connection with the making of arrangements under Article 15 for the provision of accommodation in Great Britain, the Channel Islands or the Isle of Man.".

Rules regarding courses for persons who are or wish to become social workers

46. In section 10 of the Health and Personal Social Services Act (Northern Ireland) 2001 (c. 3) (approval of courses in relevant social work), in subsection (3) (rules) for paragraph (a) there shall be substituted the following paragraph—

> "(a) about the provision of courses, including their content and methods of completing them;".

Arrangements for provision of pharmaceutical services by pharmacists

47. In Article 63 of the Health and Personal Social Services (Northern Ireland) Order 1972 (NI 14) (arrangements for pharmaceutical services), in paragraph (1)(bb) (provision of listed drugs and medicines and listed appliances by registered nurse, midwife or health visitor), after the word "by" there shall be inserted the words "a pharmacist or".

Regulations, orders and directions

48.—(1) Regulations under this Order shall be subject to negative resolution.

(2) Regulations and orders under this Order may contain—

(a) any supplementary, incidental or consequential provision;

(b) any transitory, transitional or saving provision,

which the Department considers necessary or expedient.

(3) Section 17(2) of the Interpretation Act (Northern Ireland) 1954 (c. 33) shall apply to a direction given by the Department under this Order as if the direction were a statutory instrument.

Transitional provisions and savings

49. The transitional provisions and savings set out in Schedule 3 shall have effect.

Amendments and repeals

50.—(1) The statutory provisions set out in Schedule 4 shall have effect subject to the amendments there specified.

(2) The statutory provisions set out in Schedule 5 are hereby repealed to the extent mentioned in the third column of that Schedule.

A. K. Galloway
Clerk of the Privy Council

SCHEDULES

Schedule 1

Article 3(2)

THE NORTHERN IRELAND HEALTH AND PERSONAL SOCIAL SERVICES REGULATION AND IMPROVEMENT AUTHORITY

Status

1. The Regulation and Improvement Authority shall not be regarded as the servant or agent of the Crown or as enjoying any status, immunity or privilege of the Crown; and its property shall not be regarded as property of, or property held on behalf of, the Crown.

General powers

2.—(1) Subject to any directions given by the Department, the Regulation and Improvement Authority may do anything which appears to it to be necessary or expedient for the purpose of, or in connection with, the exercise of its functions.

(2) That includes, in particular—

(a) co-operating with other public authorities in the United Kingdom;

(b) acquiring and disposing of land and other property; and

(c) entering into contracts.

General duty

3. The Regulation and Improvement Authority shall carry out its functions effectively, efficiently and economically.

Membership

4. The Regulation and Improvement Authority shall consist of a chairman and other members appointed by the Department.

Appointment, procedure etc.

5. The Department may by regulations make provision as to—

(a) the appointment of the chairman and other members (including the number, or limits on the number, of members who may be appointed and any conditions to be fulfilled for appointment);

(b) the tenure of office of the chairman and other members (including the circumstances in which they cease to hold office or may be removed or suspended from office);

(c) the appointment of, constitution of and exercise of functions by committees and sub-committees (including committees and sub-committees which consist of or include persons who are not members of the Regulation and Improvement Authority); and

(d) the procedure of the Regulation and Improvement Authority and any committees or sub-committees (including the validation of proceedings in the event of vacancies or defects in appointment).

Remuneration and allowances

6.—(1) The Regulation and Improvement Authority may pay to its chairman, to any other member of the Authority and to any member of a committee or sub-committee who is not a member of the Authority, such remuneration and allowances as the Department may determine.

(2) If the Department so determines, the Regulation and Improvement Authority shall make provision for the payment of such pension, allowance or gratuities as the Department may determine to or in respect of a person who is or has been the chairman or any other member of the Authority.

(3) If the Department determines that there are special circumstances that make it right for a person ceasing to hold office as chairman of the Regulation and Improvement Authority to receive compensation, the Authority shall pay to him such compensation as the Department may determine.

(4) Any determination of the Department under this paragraph shall be subject to the approval of the Department of Finance and Personnel.

Chief executive

7.—(1) There shall be a chief executive of the Regulation and Improvement Authority who shall be a member of its staff and shall be responsible to it for the general exercise of its functions.

(2) The first chief executive shall be appointed by the Department on such terms and conditions as the Department may determine.

(3) Subject to paragraph 8(3), any chief executive subsequent to the first shall be appointed by the Regulation and Improvement Authority on such terms and conditions as the Authority may determine.

(4) An appointment under sub-paragraph (3) requires the approval of the Department.

Staff

8.—(1) The Regulation and Improvement Authority may appoint such other staff as it considers appropriate.

(2) Subject to sub-paragraph (3), appointments under this paragraph shall be on such terms and conditions as the Regulation and Improvement Authority may determine.

(3) The Department may give directions as to—

(a) the appointment of staff under this paragraph and paragraph 7(3) (including any conditions to be fulfilled for appointment); and

(b) the terms and conditions of appointment of staff under the provisions mentioned in head (a).

(4) Different directions may be given under sub-paragraph (3) in relation to different categories of staff.

Delegation of functions

9. The Regulation and Improvement Authority may arrange for the discharge of any of its functions by a committee, sub-committee, member or member of staff of the Authority or any other person.

Arrangements for the use of staff

10. The Department may by regulations provide for arrangements under which—

(a) members of staff of the Regulation and Improvement Authority are placed at the disposal of a prescribed person for the purpose of discharging, or assisting in the discharge of, prescribed functions of that person; or

(b) members of staff of a prescribed person are placed at the disposal of the Regulation and Improvement Authority for the purpose of discharging, or assisting in the discharge of, any functions of the Authority.

Payments to the Regulation and Improvement Authority

11. The Department may make payments to the Regulation and Improvement Authority of such amounts, at such times and on such conditions (if any) as it considers appropriate.

Accounts

12.—(1) The Regulation and Improvement Authority shall—

(a) keep proper accounts and proper records in relation to the accounts; and

(b) prepare a statement of accounts in respect of each financial year.

(2) The statement of accounts shall—

(a) be in such form; and

(b) contain such information,

as the Department may, with the approval of the Department of Finance and Personnel, direct.

(3) The Regulation and Improvement Authority shall, within such period after the end of each financial year as the Department may direct, send copies of the statement of accounts relating to that year to—

(a) the Department; and

(b) the Comptroller and Auditor General for Northern Ireland.

(4) The Comptroller and Auditor General shall—

(a) examine, certify and report on every statement of accounts sent to him by the Regulation and Improvement Authority under this paragraph; and

(b) send a copy of his report to the Department.

(5) The Department shall lay a copy of the statement of accounts and of the Comptroller and Auditor General's report before the Assembly.

(6) In this paragraph "financial year" means—

(a) the period beginning with the date on which the Regulation and Improvement Authority is established and ending with the next 31st March following that date; and

(b) each successive period of twelve months ending with 31st March.

Application of seal and evidence

13. The application of the seal of the Regulation and Improvement Authority shall be authenticated by the signature—

(a) of any member of the Regulation and Improvement Authority; or

(b) of any other person who has been authorised by the Regulation and Improvement Authority (whether generally or specifically) for that purpose.

14. A document purporting to be duly executed under the seal of the Regulation and Improvement Authority or to be signed on its behalf shall be received in evidence and, unless the contrary is proved, taken to be so executed or signed.

Default powers of Department

15.—(1) The powers conferred by this paragraph are exercisable by the Department if it is satisfied that the Regulation and Improvement Authority—

(a) has without reasonable excuse failed to discharge any of its functions; or

(b) in discharging any of its functions, has without reasonable excuse failed to comply with any directions given to it under Article 6(2) in relation to those functions.

(2) The Department may—

(a) make an order declaring the Council to be in default; and

(b) direct the Council to discharge such of its functions, and in such manner and within such period or periods, as may be specified in the direction.

(3) If the Regulation and Improvement Authority fails to comply with the Department's direction under sub-paragraph (2), the Department may—

(a) discharge the functions to which the direction relates itself; or

(b) make arrangements for any other person to discharge those functions on its behalf.

Transfer of staff to the Regulation and Improvement Authority

16.—(1) The Department may by order make a scheme for the transfer to the Regulation and Improvement Authority of any eligible employee.

(2) The scheme may apply to all eligible employees or to such of them as are specified in the scheme.

(3) The Department shall not make an order under this paragraph unless such requirements as may be prescribed about consultation have been complied with in relation to each of the employees to be transferred under the scheme.

(4) The contract of employment of an employee transferred under the scheme—

(a) is not terminated by the transfer; and

(b) has effect from the date of transfer as if originally made between the employee and the Regulation and Improvement Authority.

(5) Where an employee is transferred under the scheme—

(a) all the rights, powers, duties and liabilities of Boards under or in connection with the contract of employment are by virtue of this sub-paragraph transferred to the Regulation and Improvement Authority on the date of transfer; and

(b) anything done before that date by or in relation to Boards in respect of that contract or the employee is to be treated from that date as having been done by or in relation to the Regulation and Improvement Authority.

(6) Sub-paragraph (5) does not prejudice the generality of sub-paragraph (4).

(7) This paragraph does not prejudice any right of an employee to terminate his contract of employment if a substantial change is made to his detriment in his working conditions; but no such

right arises by reason only that, by virtue of this paragraph, the identity of his employer changes unless the employee shows that, in all the circumstances, the change is a significant change and is to his detriment.

(8) In this paragraph—

"date of transfer" means the date of transfer determined under the scheme in relation to the employee;

"eligible employee" means a person who is employed under a contract of employment with a Health and Social Services Board on work which would have continued but for the provisions of this Order.

(9) An order under this paragraph shall not be a statutory rule for the purposes of the Statutory Rules (Northern Ireland) Order 1979 (NI 12).

Transfer of assets and liabilities to the Regulation and Improvement Authority

17.—(1) The Department may by order transfer or provide for the transfer to the Regulation and Improvement Authority, with effect from such date as may be specified in the order, of such of the assets and liabilities of the Department or of a Health and Social Services Board as, in the Department's opinion, need to be transferred to the Regulation and Improvement Authority for the purpose of enabling it to carry out its functions.

(2) An order under this paragraph may create or impose such new rights or liabilities in respect of what is transferred or what is retained by the Department or a Health and Social Services Board as appear to the Department to be necessary or expedient.

(3) Nothing in this paragraph affects the power of the Department or any power of a Health and Social Services Board to transfer assets or liabilities to the Regulation and Improvement Authority otherwise than under sub-paragraph (1).

(4) Stamp duty shall not be chargeable in respect of any transfer to the Regulation and Improvement Authority effected by or by virtue of an order under this paragraph.

(5) Where an order under this paragraph provides for the transfer—

(a) of land held on lease from a third party, or

(b) of any other asset leased or hired from a third party or in which a third party has an interest,

the transfer shall be binding on the third party notwithstanding that, apart from this sub-paragraph, it would have required his consent or concurrence.

(6) Any assets and liabilities which are to be transferred to the Regulation and Improvement Authority shall be identified by agreement between the Authority and the Department or, in default of agreement, by direction of the Department.

(7) Where, for the purpose of a transfer pursuant to an order under this paragraph, it becomes necessary to apportion any assets or liabilities, the order may contain such provisions as appear to the Department to be appropriate for the purpose; and where any such assets fall within sub-paragraph (5), the order shall contain such provisions as appear to the Department to be appropriate to safeguard the interests of third parties, including, where appropriate, provision for the payment of compensation of an amount to be determined in accordance with the order.

(8) In the case of any transfer made by or pursuant to an order under this paragraph, a certificate issued by the Department that any asset or liability specified in the certificate is vested in the Regulation and Improvement Authority shall be conclusive evidence of that fact for all purposes.

(9) An order under this paragraph may include provision for matters to be settled by arbitration by a person determined in accordance with the order.

(10) In this paragraph "third party" means a person other than the Department or a Health and Social Services Board.

(11) An order under this paragraph shall not be a statutory rule for the purposes of the Statutory Rules (Northern Ireland) Order 1979 (NI 12).

SCHEDULE 2

THE CARE TRIBUNAL

Constitution of Care Tribunal

1.—(1) There shall be appointed—

(a) a panel of persons ("the chairmen's panel") who may serve as chairmen of the Care Tribunal; and

(b) a panel of persons ("the lay panel") who may serve as the other two members of the Care Tribunal apart from the chairman.

(2) The Care Tribunal shall consist of—

(a) a chairman nominated by the First Minister and deputy First Minister acting jointly from the chairmen's panel; and

(b) two other persons nominated by the Department from the lay panel.

Appointment of the panels

2.—(1) The members of the chairmen's panel shall be appointed by the First Minister and deputy First Minister acting jointly.

(2) No person may be appointed a member of the chairmen's panel unless he is a barrister or solicitor of at least ten years' standing.

(3) The members of the lay panel shall be appointed by the Department.

(4) No person may be appointed member of the lay panel unless he satisfies such requirements as may be prescribed.

Tenure of office

3.—(1) Each member of the chairmen's panel or lay panel shall hold and vacate office under the terms of the instrument under which he is appointed.

(2) A member of the chairmen's panel may resign office by notice in writing to the First Minister and deputy First Minister.

(3) A member of the chairmen's panel may be removed from the panel by the First Minister and deputy First Minister acting jointly on the ground of incapacity or misbehaviour.

(4) A member of the lay panel may resign office by notice in writing to the Department.

(5) A member of the lay panel may be removed from the panel by the Department on the ground of incapacity or misbehaviour.

(6) A member of the chairmen's panel or lay panel is eligible for re-appointment if he ceases to hold office (otherwise than under sub-paragraph (3) or (5)).

Staff and accommodation

4. The Department may, with the consent of the Department of Finance and Personnel, provide such staff and accommodation as the Care Tribunal may require.

Remuneration and expenses

5.—(1) The Department may pay any person, in respect of his service as a member of the Care Tribunal, such remuneration and allowances as the Department may, with the consent of the Department of Finance and Personnel, determine.

(2) The Department may defray the expenses of the Care Tribunal to such amount as the Department may, with the consent of the Department of Finance and Personnel, determine.

Attendance allowances

6. The Department may pay such allowances for the purpose of or in connection with the attendance of persons at the Care Tribunal as the Department may, with the consent of the Department of Finance and Personnel, determine.

Temporary provision

7. Until the commencement of section 5(1) of the Justice (Northern Ireland) Act 2002 (c. 26) references in this Schedule to the First Minister and deputy First Minister or to the First Minister and deputy First Minister acting jointly shall be construed as references to the Lord Chancellor.

SCHEDULE 3

TRANSITIONAL PROVISIONS AND SAVINGS

Fostering agencies

1. The Department may by regulations provide that, if prescribed requirements are satisfied, Article 12 shall apply, during the prescribed period, to a person running a fostering agency who has made an application for registration under Article 13(1) as if that person were unconditionally registered under Part III.

Voluntary adoption agencies

2.—(1) Where a body is, before the commencement of Article 14, registered under Article 4 of the Adoption (Northern Ireland) Order 1987 (NI 22) (registration of adoption societies), Part III shall, if prescribed requirements are satisfied, have effect after that commencement as if any person carrying on or managing the body were registered under Part III in respect of it, either—

(a) unconditionally; or

(b) subject to such conditions as may be prescribed.

(2) Any application made before the commencement of Article 13 for registration under Article 4 of the Adoption (Northern Ireland) Order 1987 shall be treated after that commencement as an application made under Article 13(1) to the Regulation and Improvement Authority for registration under Part III.

(3) The Department may by order subject to negative resolution make such further transitional provision in relation to the repeal by this Order of provisions of the Adoption (Northern Ireland) Order 1987 as it considers appropriate.

Saving for amendments

3. The amendments made by paragraphs 2, 3(3) and (4) and 5 of Schedule 1 to the Registered Homes (Northern Ireland) Order 1992 (NI 20) shall continue to have effect notwithstanding the repeal of those paragraphs by this Order, but subject to any further amendments made by this Order.

SCHEDULE 4

AMENDMENTS

The Superannuation (Northern Ireland) Order 1972 (NI 10)

In Schedule 1 (employments to which Article 3 of that Order applies) at the end there shall be added—

> *"Employment by the Northern Ireland Health and Personal Social Services Regulation and Improvement Authority.".*

The Health and Personal Social Services (Northern Ireland) Order 1972 (NI 14)

In Article 50(1) (power of inspection), for "the Registered Homes (Northern Ireland) Order 1992" substitute "Part III of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003".

The Northern Ireland Assembly Disqualification Act 1975 (c. 25)

In Part II of Schedule 1 (bodies of which all members are disqualified), the following entry shall be inserted at the appropriate place—

> *"The Northern Ireland Health and Personal Social Services Regulation and Improvement Authority.".*

The Mental Health (Northern Ireland) Order 1986 (NI 4)

In Article 2(2) (interpretation)—

(a) in the definition of "nursing home" for the words from "Article 16" to the end substitute "Article 11 of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003";

(b) for the definition of "residential care home" substitute—

> ""residential care home" has the meaning assigned to it by Article 10 of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003;".

The Adoption (Northern Ireland) Order 1987 (NI 22)

In Article 2(2) (interpretation) after the definition of “adoption rules” insert the following definition—

> ““appropriate voluntary organisation” means a voluntary organisation which is an adoption society in respect of which a person is registered under Part III of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003;”.

In Article 3 (The Adoption Service)—

(a) in paragraph (1) for “registered adoption societies” substitute “appropriate voluntary organisations”;

(b) in paragraph (3) for “a registered adoption society” substitute “an appropriate voluntary organisation”.

In Article 5(2) (power of Department to make directions where registration of adoption society is cancelled or expires), for the words from the beginning to “expires” substitute “Where, by virtue of the cancellation of the registration of any person under Part III of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003, a body has ceased to be an appropriate voluntary organisation”.

In Article 8 (inactive or defunct adoption societies)—

(a) in paragraph (1) for the words from “registered” to “Article 5,” substitute “body which is or has been an appropriate voluntary organisation”; and

(b) for “society” in each place where it occurs substitute “organisation”.

In Article 10 (regulation of adoption agencies) after paragraph (1) insert the following paragraph—

“(1A) Regulations under paragraph (1) may in particular make, in relation to an appropriate voluntary organisation any provision which regulations under Article 23(2) or (7) of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003 may make in relation to a fostering agency (within the meaning of that Order).”.

In Article 11 (restriction on arranging adoptions and placing children)—

(a) in paragraph (2) for the words from “registered under Article 4” substitute “an appropriate voluntary organisation”;

(b) in paragraph (3)(a) for “which is not an adoption agency” substitute

“which is not—

(i) a Board or HSS trust; or

(ii) a voluntary adoption agency within the meaning of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003 in respect of which he is registered;”.

In Article 23 (enquiries to be made of Board etc.)—

(a) for “a registered adoption society” substitute “an appropriate voluntary organisation”;

(b) for “the society” in both places where it occurs substitute “the organisation”.

In Article 33(2)(a)(ii) (meaning of “protected child”), for “children’s home or voluntary home” substitute “children’s home in respect of which a person is registered under Part III of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003”.

In Article 54(3)(d)(i) (disclosure of birth records of adopted children), for “registered under Article 4” substitute “being an appropriate voluntary organisation”.

The Disabled Persons (Northern Ireland) Act 1989 (c. 10)

In section 2(5) for paragraph (d) substitute the following paragraph—

"(d) in a residential care home or nursing home within the meaning of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003; or".

The Children (Northern Ireland) Order 1995 (NI 2)

In Article 2(2) (interpretation)—

(a) after the definition of "Adoption Order" insert the following definition—

> ""appropriate children's home" has the meaning given in Article 27(10);";

(b) after the definition of "care order" insert the following definition—

> ""Care Tribunal" means the tribunal established by Article 44 of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003;";

(c) in the definition of "children's home" for the words from "given" to the end substitute "assigned to it by Article 9 of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003";

(d) in the definition of "nursing home" for the words from "Article 16" to the end substitute "Article 11 of the Health and Personal Social Services (Quality, Improvement and Regulation) Act (Northern Ireland) 2003";

(e) after the definition of "prescribed" insert the following definition—

> ""private children's home" means a children's home—
>
> (a) in respect of which a person is registered under Part III of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003; and
>
> (b) which is not a home provided under Part VII or a voluntary home;";

(f) after the definition of "registered children's home" insert the following definition—

> ""Regulation and Improvement Authority" means the Northern Ireland Health and Personal Social Services Regulation and Improvement Authority;";

(g) in the definition of "residential care home" for the words from "Article 3" to the end substitute "Article 10 of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003";

In Article 27 (accommodation and maintenance for children looked after by an authority)—

(a) in paragraph (2), for sub-paragraphs (b) to (e) substitute the following sub-paragraph—

> "(aa) maintaining him in an appropriate children's home;";

(b) after paragraph (9) add the following paragraph—

> "(10) In this Order "appropriate children's home" means a children's home in respect of which a person is registered under Part III of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003.".

In Article 35 (advice and assistance for certain children) as it has effect before the commencement of the Children (Leaving Care) Act (Northern Ireland) 2002, in paragraph (2)(c) for "registered" substitute "private".

In Article 35 (persons qualifying for advice and assistance) as it has effect after the commencement of the Children (Leaving Care) Act (Northern Ireland) 2002, in paragraph (2)(c) for "registered" substitute "private".

In Article 35C (information), in paragraph (2)(a) for "registered" substitute "private".

In Article 37 (supplementary), in paragraph (4)(a) for "registered" substitute "private".

In Article 70(1) (refuges for children at risk), for “registered” substitute “private”.

In Article 74(1) (definition of “voluntary home”, etc.), for the definition of “voluntary home” substitute the following definition—

> ““voluntary home” means a children’s home which is carried on by a voluntary organisation;”.

In Article 75(1) (provision of accommodation for children by voluntary organisations), for sub-paragraphs (b) to (e) substitute the following sub-paragraph—

> “(aa) maintaining him in an appropriate children’s home;”.

In Article 77 (duties of an authority in relation to children provided with accommodation by voluntary organisations) in paragraph (5)(c), for “Article 89” substitute “Article 23 of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003”.

In Article 78 (persons disqualified from carrying on, or being employed in, voluntary homes)—

- (a) in paragraphs (1)(a) and (2)(a), for “authority” substitute “Regulation and Improvement Authority”;
- (b) in paragraphs (1)(b) and (2)(b), for “the consent of the authority” substitute “its consent”;
- (c) in paragraph (3)—
  - (i) for “an authority” substitute “the Regulation and Improvement Authority”;
  - (ii) for “the authority” substitute “it”;
  - (iii) for sub-paragraph (b) substitute—
    - “(b) the applicant’s right to appeal under Article 78A against the refusal to the Care Tribunal; and”.

After Article 78 insert—

> “**Appeal against refusal of consent under Article 78**
>
> **78A.**—(1) An appeal against a decision of the Regulation and Improvement Authority under Article 78 shall lie to the Care Tribunal.
>
> (2) On an appeal the Care Tribunal may confirm the decision of the Regulation and Improvement Authority or direct it to give the consent in question.”.

In the heading to Part IX, before “CHILDREN'S HOMES” insert “PRIVATE”.

In Article 90(3) (references to an authority), before “children’s home” insert “private”.

In Article 91(4) (circumstances in which a person may foster more than three children without being treated as carrying on a children’s home), after “treated” insert “for the purposes of this Order and the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003”.

In Article 92 (duties of person carrying on children’s home)—

- (a) in the heading,
- (b) in paragraph (1), and
- (c) in paragraph (4),

before “children’s home” insert “private”.

In Article 93 (duties of an authority)—

- (a) in paragraphs (1), (2), (3)(a), (4) and (5)(a), before “children’s home” insert “private”;
- (b) in paragraph (5)(c) for “Article 105” substitute “Article 23 of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003”.

In Article 94 (persons disqualified from carrying on, or being employed in, children’s homes)—

(a) in the heading before "children's homes" insert "private";

(b) in paragraphs (1)(a) and (2)(a), for "authority" substitute "Regulation and Improvement Authority";

(c) in paragraphs (1)(b) and (2)(b), for "the consent of the authority" substitute "its consent";

(d) in paragraph (3)—

  (i) for "an authority" substitute "the Regulation and Improvement Authority";

  (ii) for "the authority" substitute "it";

  (iii) for sub-paragraph (b) substitute—

    "(b) the applicant's right to appeal under Article 94A against the refusal to the Care Tribunal; and".

After Article 94 insert the following Article—

"**Appeal against refusal of consent under Article 94**

94A.—(1) An appeal against a decision of the Regulation and Improvement Authority under Article 94 shall lie to the Care Tribunal.

(2) On an appeal the Care Tribunal may confirm the decision of the Regulation and Improvement Authority or direct it to give the consent in question.".

In Article 105(1)(a) (regulations as to placing of children), for "registered" substitute "private".

In Article 106 (interpretation)—

(a) in paragraph (1) in the definition of "privately fostered child" after "accommodation" insert "in their own home";

(b) in paragraph (2)(a) for ", 91 and 95" substitute "and 91";

(c) after paragraph (3) add the following paragraph—

  "(3A) The Department may by regulations make provision as to the circumstances in which a person who provides accommodation to a child is, or is not, to be treated as providing him with accommodation in the person's own home.".

In Article 107(3) (privately fostered children further defined)—

(a) sub-paragraph (b) shall cease to have effect;

(b) for "sub-paragraphs (b)" in both places where it occurs substitute "sub-paragraphs (c)".

In Article 149(5) (persons required to furnish information, etc.), after sub-paragraph (i) add the following sub-paragraph—

"(j) any person carrying on a fostering agency (within the meaning of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003)".

In Article 153(2) (representations concerning child care training), for sub-paragraph (a) substitute the following sub-paragraph—

"(a) the Northern Ireland Social Care Council;".

In Article 176 (children accommodated in schools)—

(a) in paragraph (2) for "within the area of an authority, the authority" substitute "the Regulation and Improvement Authority";

(b) in paragraph (3)—

  (i) for "an authority" substitute "it";

(ii) for "within the authority's area, the authority" substitute "the Regulation and Improvement Authority";

(c) for paragraph (4) substitute the following paragraph—

> "(4) Where accommodation is, or is to be, provided for a child by any school, a person authorised by the Regulation and Improvement Authority may, for the purpose of enabling that Authority to discharge its duty under this Article, enter at any time any premises which are, or are to be, premises of the school.".

In Schedule 5 (foster parents: limits on number of foster children), in paragraph 5(1) after "treated" insert "for the purposes of this Order and the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003".

The Commissioner for Complaints (Northern Ireland) Order 1996 (NI 7)

In Schedule 2 (bodies subject to investigation), the following entry shall be inserted at the appropriate place—

> *"The Northern Ireland Health and Personal Social Services Regulation and Improvement Authority.".*

The Health and Personal Social Services Act (Northern Ireland) 2001 (c. 3)

In section 15 (appeals to the Social Care Tribunal)—

(a) in subsections (2), (3) and (5) for "a Social" substitute "the";

(b) in subsection (4), for "A Social" substitute "The".

For section 22 (interpretation) substitute—

> "**Interpretation of this Part**
>
> **22.** In this Part "child", "children's home", "day care setting", "domiciliary care agency", "nursing home", "personal care", "registered care home", "residential family centre", "school" and "undertaking" have the same meanings as in the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003.".

The Adoption (Intercountry Aspects) Act (Northern Ireland) 2001 (c. 11)

In section 2 (Central Authority and accredited bodies)—

(a) after subsection (2) insert the following subsection—

> "(2A) A voluntary adoption agency in respect of which a person is registered under Part III of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003 is an accredited body for the purposes of the Convention if, in accordance with the conditions of the registration, the agency may provide facilities in respect of Convention adoptions and adoptions effected by Convention adoption orders.";

(b) for subsection (5) substitute the following subsection—

> "(5) In this section "voluntary adoption agency" has the same meaning as in the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003; and expressions which are also used in the Adoption (Northern Ireland) Order 1987 (NI 22) ("the 1987 Order") have the same meaning as in that Order.".

The Justice (Northern Ireland) Act 2002 (c. 26)

In Schedule 6, in the entry relating to Social Care Tribunals, for "Social Care Tribunals" substitute "the Care Tribunal".

The Protection of Children and Vulnerable Adults (Northern Ireland) Order 2003 (NI 00)

In Article 2(2) (interpretation: general)—

(a) for the definitions of "nursing agency" and "nursing home" substitute the following definition—

> ""nursing agency" and "nursing home" have the same meanings as in the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003;";

(b) for the definition of "private hospital" substitute the following definition—

> ""the Regulation and Improvement Authority" means the Northern Ireland Health and Personal Social Services Regulation and Improvement Authority;";

(c) in the definition of "residential care home", for the words from "meaning" to the end substitute "same meaning as in the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003".

In Article 6 (power of other authorities to refer)—

(a) in paragraph (2), after sub-paragraph (c) insert the following sub-paragraph—

> "(cc) the Regulation and Improvement Authority;";

(b) in paragraph (3), after sub-paragraph (c) insert the following sub-paragraph—

> "(cc) in relation to the Regulation and Improvement Authority, any of its functions;".

In the following provisions, for "a Social" substitute "the"—

Article 11(1), (2) and (3) (appeals against inclusion in list);

Article 12(1) (application for removal from list);

Article 13(1) (conditions for applications under Article 12);

Article 15(4), (5)(a) and (6) (list in connection with prohibiting or restricting employment in schools, etc.);

Article 18(2)(g) (accredited organisations);

Article 27(1) (review of disqualification);

Article 42(1) and (2) (appeals against inclusion in list);

Article 43(1) (application for removal from list);

Article 44(1) (conditions for application under Article 43).

In Article 34(1) (interpretation of Chapter II of Part II), in the definition of "children's home" for the words from "meaning" to the end substitute "same meaning as in the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003".

In Article 38 (power of other authorities to refer)—

(a) in paragraph (2), for sub-paragraph (a) substitute the following sub-paragraph—

> "(a) the Regulation and Improvement Authority;";

(b) in paragraph (3), for sub-paragraph (a) substitute the following sub-paragraph—

> "(a) in relation to the Regulation and Improvement Authority, any of its functions;".

In Article 48 (interpretation of Part III)—

(a) in paragraph (1)(b), for "or at a private hospital" substitute ", an independent hospital, an independent clinic or an independent medical agency";

(b) in paragraph (6)(c), for "or at a private hospital" substitute ", an independent hospital, an independent clinic or an independent medical agency";

(c) in paragraph (7)(c), for "a private hospital" substitute "an independent hospital, independent clinic or independent medical agency";

(d) for paragraph (11) substitute—

> "(11) In this Part the following expressions have the same meaning as in the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003—
>
> "domiciliary care agency";
>
> "independent clinic";
>
> "independent hospital";
>
> "independent medical agency".".

Schedule 5

Article 50(2)

REPEALS

Short Title	Extent of repeal
The Nursing Homes and Nursing Agencies Act (Northern Ireland) 1971 (c. 32).	The whole Act.
The Nurses, Midwives and Health Visitors Act 1979 (c. 36).	In Schedule 7 paragraphs 19 to 22.
The Employment (Miscellaneous Provisions) (Northern Ireland) Order 1981 (NI 20).	Article 11(5)(b) and (6).
The Adoption (Northern Ireland) Order 1987 (NI 22).	In Article 2(2) the definition of "registered adoption society".
	Article 4.
	In Article 5, paragraph (1) and in paragraph (2) the word "concerned".
	Article 6.
	Article 7.
	Schedule 1.
The Registered Homes (Northern Ireland) Order 1992 (NI 20).	The whole Order.
The Children (Northern Ireland) Order 1995 (NI 2).	In Article 2(2) the definition of "registered children's home".

Short Title	Extent of repeal
	Article 73(1)(b) and (c) and (2). Article 74(2) and (3). Articles 79 to 88. Article 89(1)(b) and (c) and (2)(a) to (e) and (g) to (l). Article 90(1). Article 91(1) to (3). Articles 95 to 104. Article 105(1)(b) and (c), (2)(a) to (e) and (g) to (k) and (m). Article 107(3)(b). In Article 152(1)(b) the words "or voluntary home". In Schedule 9 paragraphs 188 to 190.
The Arbitration Act 1996 (c. 23).	In Schedule 3 paragraph 58.
The Nurses, Midwives and Health Visitors Act 1997 (c. 24).	In Schedule 4 paragraph 5.
The Health and Personal Social Services Act (Northern Ireland) 2001 (c. 3).	Section 15(1), (6) and (7). Sections 20 and 21.
The Adoption (Intercountry Aspects) Act (Northern Ireland) 2001 (c. 11).	Section 8.
The Justice (Northern Ireland) Act 2002 (c. 26).	In Schedule 3 paragraphs 26 to 28.
The Protection of Children and Vulnerable Adults (Northern Ireland) Order 2003 (NI 00).	In Article 6(3)(a) the words "and Article 176". In the cross-heading immediately preceding Article 42 the word "Social". Part IV.

EXPLANATORY NOTE

(This note is not part of the Order)

This Order establishes the Northern Ireland Health and Personal Social Services Regulation and Improvement Authority and makes provision for the registration and regulation of certain establishments and agencies.

It also makes provision relating to the quality of health and personal social services and to adoption, fostering and children under 12.

Article 45 enable regulations to be made regarding arrangements for the provision of accommodation outside Northern Ireland. Article 46 relates to rules about social work courses. Article 47 enables regulations to be made regarding arrangements for the provision of certain pharmaceutical services by pharmacists.

January 2003

PROMOTING MENTAL HEALTH

Strategy & Action Plan 2003-2008

Investing for Health

Department of Health, Social Services and Public Safety
An Roinn Sláinte, Seirbhísí Sóisialta agus Sábháilteachta Poiblí

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PROMOTING MENTAL HEALTH

Investing for Health

CHAPTER 1

WHY WE NEED A STRATEGY

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WHY WE NEED A STRATEGY

1.1 In the Programme for Government, the Executive committed itself to five priorities for action, one of which was working for a healthier people. Within this priority, it undertook to take specific measures to promote mental and emotional health and reduce suicides.

1.2 The *'Investing for Health'* Strategy provides the framework for the attack on preventable disease, ill-health and health inequalities. It identifies mental health as a priority and sets a target:

"To reduce the proportion of people with a potential psychiatric disorder (as measured by the GHQ –12* score) by a tenth by 2010."

*This is a set of twelve questions from the General Health Questionnaire which indicates the possible presence of psychiatric disorder.

The Promoting Mental Health Strategy outlines an integrated approach, which addresses the wider determinants of mental health and focuses particularly on inequalities.

1.3 Mental health problems are among the most common forms of ill health. They place a heavy burden on individuals, their families and friends and the community at large. They also impose substantial economic costs on the Health Service and society as a whole. It is estimated that as many as 1 in 6 people, at any point in time, suffer from a diagnosed condition such as depression or anxiety. Between 10%-20% of our teenagers will suffer from depression at some time. The Health and Social Wellbeing Survey[1] shows that people in Northern Ireland are at greater risk of mental ill health than people in England and Scotland. Many factors affect mental and emotional health. These are outlined in Appendix 1. Some, such as poverty and community conflict, affect people here to a greater extent than elsewhere.

1.4 Increasing recognition of mental illnesses, notably depression, as a major public health issue has led national and international public policies to place greater emphasis on improving the population's mental and emotional health status.

1.5 Recent evidence based policies adopt a health improvement approach, which takes a broader view than the traditional psychiatric model of mental health. This approach is directed at promoting good mental health, preventing mental ill health and ensuring early intervention when mental health problems occur. It involves looking beyond prevention, to the relationship between mental well-being and physical health; behavioural problems; violence; child abuse; domestic violence; drug and alcohol misuse; living and working conditions such as homelessness, poverty, and unemployment; and risk taking behaviour such as smoking and unsafe sex. It means addressing the mental health impact of public policies, programmes and plans.

1.6 Everyone has mental health needs, whether or not they have a diagnosis of mental illness. Mental and emotional health promotion involves any action to enhance the mental wellbeing of individuals, families, organisations or communities.

1.7 Mental health promotion works at three levels: and at each level, is relevant to the whole population, to individuals at risk, vulnerable groups and people with mental health problems.

- **Strengthening individuals** – or increasing emotional resilience through interventions to promote self-esteem, life and coping skills, e.g. communicating, negotiating, relationship and parenting skills.
- **Strengthening communities** – this involves increasing social inclusion and participation, improving neighbourhood environments, developing health and social services which support mental health, anti-bullying strategies at school, workplace health, community safety, childcare and self-help networks.
- **Reducing structural barriers to mental health** - through initiatives to reduce discrimination and inequalities and to promote access to education, meaningful employment, housing, services and support for those who are vulnerable.[2]

1.8 The Department of Health, Social Services and Public Safety (DHSSPS) has consulted on the draft mental health strategy "Minding our Health"[3] published in April 2000. Responses to the consultation have helped to shape this Strategy and Action Plan. In addition, in the responses to the '*Investing for Health'* consultation process mental health was the issue most highlighted as a priority for action. The voluntary and community sectors in particular highlighted the issue in relation to disadvantaged groups who may be vulnerable to mental health problems. These respondents drew attention to the importance of social support and personal and social development.

1.9 Promoting Social Inclusion (PSI) is an element of the New Targeting Social Need policy which focuses on a series of priority issues to be tackled to improve and enhance the life and circumstances of the most deprived and marginalized people in society.

1.10 The Department has established a cross-department 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 strategy through which relevant agencies will work together to systematically tackle them. This Strategy will support their work.

1.11 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. DHSSPS together with its associated bodies, conducted a 2-stage joint consultation exercise on the equality implications of all their policies between December 2000 and June 2001. This helped to identify priorities for an Equality Impact Assessment programme which includes in year 1 the promotion of positive mental health as a new policy requiring Equality Impact Assessment (EQIA). A Working Group representative of the main interests involved, was established to develop the Strategy and an EQIA.

1.12 The Human Rights Act 1998 came fully into force in October 2000. It provides additional focus and emphasis to the rights and freedoms of individuals guaranteed under the European Convention on Human Rights. There are some 18 Convention rights and protocols which range from the Right to Life to the Right to Education. The Act requires legislation, wherever enacted, to be interpreted as far as possible in a way which is compatible with the Convention rights; makes it unlawful for a public authority to act incompatibly with the Convention rights; and, if it does, allows a case to be brought in a court or tribunal against the authority. DHSSPS will ensure that this Strategy and Action Plan is compatible with the Human Rights Act.

1.13 **Chapter 2** describes the aims of the Strategy, **Chapter 3** outlines an Action Plan to support mental and emotional wellbeing and **Chapter 4** sets out how the Strategy will be taken forward. **Annex 1** defines mental and emotional health and identifies some of its main determinants. **Annex 2** outlines the aims of mental health promotion and describes some effective interventions. **Annex 3** deals with the specific issue of suicide. **Annex 4** outlines the equality implications.

CHAPTER 2

AIMS OF THE STRATEGY

CHAPTER 2

AIMS OF THE STRATEGY

2.1 Mental health is the emotional and spiritual resilience which enables us to enjoy life and to survive pain, disappointment and sadness. It is a positive sense of wellbeing and an underlying belief in our own and others' dignity and worth.[4]

2.2 This Strategy's aims are to:

- **improve people's mental and emotional wellbeing, in particular that of people at risk or vulnerable, and people with identified mental health problems, their carers and families;**
- **prevent, or reduce the incidence and impact of, mental and emotional distress, anxiety, mental illness and suicide;**
- **raise awareness of the determinants of mental and emotional health at public, professional and policy making levels and reduce discrimination against people with mental health problems;**
- **ensure that all those with a contribution to make are knowledgeable, skilled and aware of effective practice in mental and emotional health promotion.**

2.3 These aims will be realised through an integrated partnership approach including the statutory, voluntary, community and business sectors. The partners will include organisations working in areas such as education, employment, and neighbourhood regeneration. Settings will include the home, school, community and workplace.

2.4 The Strategy sets the following target:

To reduce the proportion of people with a potential psychiatric disorder (as measured by the GHQ-12 score) to 19.5% by 2008.

(Source: Health and Wellbeing Survey. Baseline: 21% in 2001)

2.5 The Strategy will encourage policy development and support mental and emotional health in two main areas:

life circumstances – providing social and physical environments which assist people in obtaining help and resources to support them through challenges or crises; and

life skills – enabling and empowering people to improve their own mental health by promoting positive wellbeing and self esteem.

Principles

2.6 This Strategy adopts the framework of values and principles set out in the *'Investing for Health'* Strategy. In addition, the following principles are appropriate for mental health promotion. The two sets of principles provide the criteria against which interventions, services, and practices will be evaluated.

i. A holistic approach to mental health

Addressing an individual's physical, social, emotional and spiritual health in their everyday social context.

ii. Empowerment

Supporting individuals by enhancing their knowledge and skills to promote emotional wellbeing.

iii. Respect for personal dignity

Recognising that all people have dignity, and deserve social justice, fairness, respect and equality of opportunity.

Taking the Strategy Forward

2.7 The Strategy comprises a number of actions grouped under four areas:

a) policy development;

b) raising awareness and reducing discrimination;

c) improving knowledge and skills;

d) preventing suicide.

2.8 Chapter 3 sets out for each of these areas, the actions to be taken, initial target dates and the main partners.

CHAPTER 3
ACTION PLAN

CHAPTER 3

ACTION PLAN

3.1 Mental and emotional wellbeing is influenced by many factors including childhood experiences, life events, individual ability to cope, social networks, and wider social and economic circumstances. Many of these factors lie outside the control of the health and social services, and indeed of Government.

3.2 Good mental health promotion depends on expertise, resources and partnership across all sectors and disciplines. It is relevant to the implementation of a wide range of policy initiatives including New Targeting Social Need, the equality agenda, neighbourhood regeneration and community development.

3.3 To support mental and emotional wellbeing the following actions are to be taken forward:

Policy development

Action 1
The Department of Health, Social Services & Public Safety (DHSSPS) will establish a Multi-Agency Implementation Group to steer and oversee implementation of the Strategy and Action Plan.
Target Date: February 2003

Action 2
The Implementation Group will report progress on implementation of the Strategy and Action Plan annually to the Ministerial Group on Public Health.
Target Date: Ongoing

Action 3
All Departments and their Agencies will assess the health impact, including mental health, of all new major policies and programmes.
Target Date: Ongoing

Action 4
DHSSPS will in partnership with Department of Culture, Arts and Leisure (DCAL), Department of Education (DE), Department for Employment and Learning (DEL) and Department of Regional Development (DRD) continue to support and develop initiatives under the Physical Activity and Drug & Alcohol Strategies.
Target Date: Ongoing

Action 5
Health and Social Services (HSS) Boards and Trusts 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 progress annually to the Implementation Group.
Target Date: Ongoing

Action 6
HSS Boards in partnership with HSS Trusts and the voluntary and community sectors will develop programmes to improve social support and reduce isolation for those who care for people who are elderly, disabled or mentally ill.
Target Date: September 2004

Action 7
HSS Boards in partnership with all acute and community HSS Trusts will ensure that service providers have in place a policy on mental health promotion and a programme of action to support positive mental wellbeing including the availability for older adults to participate in physical activity.
Target Date: Ongoing

Action 8
DE in partnership with DHSSPS, Education & Library (Ed&L) Boards and HSS Boards will develop a policy for the promotion of mental and emotional health of children and young people.
Target Date: March 2004

Action 9
DE in partnership with DHSSPS, Health Promotion Agency (HPA), schools and the voluntary and community sectors will develop a regional educational resource for the promotion of pupils' mental health and emotional well-being including anti-bullying approaches for use in schools.
Target Date: March 2004

Action 10
Department of Enterprise, Trade and Investment (DETI) in partnership with the Health and Safety Executive will ensure that the Workplace Health Strategy addresses the issue of work-related stress.
Target Date: April 2003

Action 11
Department of Agriculture and Rural Development (DARD) and DHSSPS will support the development of a rural support network to develop appropriate intervention strategies in rural communities.
Target Date: ongoing

Action 12
The Prison Service will provide access to appropriate services to those in prison with recognised mental health problems.
Target Date: Ongoing

Raising awareness and reducing discrimination

Action 13
DHSSPS in partnership with the HPA, HSS Boards, the voluntary and community sectors will develop a public and professional information campaign to raise awareness and understanding of mental health issues and reduce the stigma attached to mental health problems.
Target Date: September 2005

Action 14
HSS Boards and HSS Trusts in partnership with Ed&L Boards and the voluntary and community sectors will ensure that information about local sources of help and support is developed, available and accessible.
Target Date: June 2003

Action 15
DE, DEL and HSS Boards and HSS Trusts will through Investing for Health Partnerships ensure that strong links are maintained between schools and local health and social services.
Target Date: Ongoing

Improving knowledge & skills

Action 16
DHSSPS in partnership with HSS Boards and professional and voluntary bodies will carry out a review of professional training to ensure that the promotion of mental health and emotional wellbeing is fully included and takes account of the particular needs of disadvantaged groups including ethnic minority, disability and sexual orientation.
Target Date: March 2005

Action 17
DE in partnership with DEL, Ed&L Boards and professional bodies will carry out a review of professional training to ensure that the promotion of mental health and emotional wellbeing is fully included and takes account of the particular needs of disadvantaged groups including ethnic minority, disability and sexual orientation.
Target Date: March 2005

Action 18
DHSSPS in partnership with the HPA, HSS Boards and HSS Trusts, the voluntary and community sectors will assess the need for and review the extent and content of parenting skills initiatives on offer and ensure that guidance, training and regular updating of staff is available.
Target Date: December 2003

Action 19
HSS Boards in partnership with HSS Trusts and the voluntary and community sectors will develop programmes aimed at improving coping capabilities among older people, particularly around times of bereavement.
Target Date: December 2004

Action 20
DE in partnership with DHSSPS, Ed&L Boards, HSS Boards and HSS Trusts will develop training to support youth workers in understanding early recognition of risk and effective approaches to support young people's mental and emotional health.
Target Date: April 2004

Preventing Suicide

3.4 Suicide is a difficult and emotive subject. It is important to raise awareness of the problem and it's causes, and to respond in a practical and effective way. The actions outlined above to promote mental health will help, but in addition the following specific actions are to be taken forward.

Action 21
DE and DEL in partnership with Ed&L Boards, schools, Youth Council for NI, HPA and HSS Boards will implement programmes on awareness of suicide for teachers and youth leaders.
Target Date: April 2004

Action 22
DE in partnership with the Youth Services, Youth Council for NI and voluntary and community sectors will continue to develop outreach work with young people in areas of need and especially young males.
Target Date: Ongoing

Action 23
HSS Boards will develop a suicide awareness programme in each Board area.
Target Date: April 2004

Action 24
HSS Boards in partnership with HSS Trusts and the voluntary and community sectors will develop a support service and provide an information booklet for those bereaved by suicide.
Target Date: April 2004

Action 25
HSS Boards and HSS Trusts in partnership with Primary Care, and voluntary and community sectors will ensure that a suicide risk assessment training programme is initiated for health and social services personnel and staff in the voluntary and community sectors working with vulnerable people.
Target Date: April 2004

Action 26
HSS Boards and HSS Trusts in co-operation with Primary Care will develop and deliver a Depression Awareness Training Programme for GPs.
Target Date: September 2004

Action 27
HSS Boards and HSS Trusts in partnership with the voluntary and community sectors will as part of policy development, consider how best to provide appropriate information on services available to people contemplating suicide.
Target Date: December 2003

Action 28
The **Prison Service** will ensure that all remand and sentenced prisoners continue to receive initial and ongoing monitoring of their mental health and assessment of the risk of suicide.
Target Date: Ongoing

Action 29
The **Prison Service** and the **Police Service** will continue to address whatever steps are necessary to avert any opportunity for suicide to take place among those at risk.
Target Date: Ongoing

Action 30
The **Prison Service** and the **Police Service** will ensure that suicide awareness is part of the in-service training for police and prison officers.
Target Date: Ongoing

CHAPTER 4
MAKING IT HAPPEN

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MAKING IT HAPPEN

4.1 It will take time and partnership working in a range of settings to achieve the overall mental health target set in the *'Investing for Health'* Strategy. The actions set out in Chapter 3, when implemented, will help to promote mental health and wellbeing and achieve the target.

Managing the Plan

4.2 The Ministerial Group on Public Health (MGPH) will be responsible for the overall monitoring of the Strategy and Action Plan. DHSSPS will establish a Multi-Agency Implementation Group to oversee and drive forward the actions outlined in Chapter 3. The Implementation Group will report progress to MGPH annually. It will also report progress to the Taskforce on Employability and Long-Term Unemployment to ensure that mental health issues are included in future policy development. The Strategy will be reviewed after five years.

Research

4.3 The Health and Wellbeing Survey 2001 has been used as a baseline to set the overall target in *'Investing for Health.'* Subsequent surveys will be used to monitor and measure progress against this target. The Implementation Group will wish to consider the need for additional research to help monitor progress.

Resources

4.4 DHSSPS will be making £200,000 available in this and the following two financial years to implement the Strategy and Action Plan.

ANNEX 1

MENTAL AND EMOTIONAL HEALTH

ANNEX 1
MENTAL AND EMOTIONAL HEALTH

1. Mental and emotional health is a resource which we need for everyday life, and which enables us to manage our lives successfully.

2. Factors which support or influence our mental health and wellbeing include: a stable and secure environment; the ability to engage in lasting meaningful relationships and maintain self-esteem; the emotional skills to manage change and survive difficulties in our lives; coping and life skills to enable us to control our lives and deal with stressful circumstances effectively.

3. Mental health and emotional wellbeing depend both on our internal psychological processes and on the values and resources of the outside world. They develop according to the support they receive from their social environments. They result in a sense of being in control of oneself and able to cope with events in the outside world.

What Affects Mental and Emotional Health

4. The natural capacity of people to make decisions about what is or is not good for them can be compromised by either internal or external factors, or both.

5. **Internal factors** which may make us more vulnerable to poor mental or emotional health include:

   - poor quality of relationships;
   - feelings of isolation;
   - experience of disharmony, conflict or alienation;
   - physical illness, infirmity or disability;
   - a lack of self-esteem.

6. **External factors** which may compromise mental or emotional wellbeing include:

   - poverty and unemployment;
   - social exclusion or discrimination;
   - poor physical environment;
   - negative peer pressures;
   - experience of abuse or violence;
   - family or community conflict or tension.

7. Many factors affect mental and emotional health. Some affect people here to a greater extent than elsewhere, such as poverty and community conflict. Others affect us irrespective of age, such as family breakdown, sexual or emotional abuse, social exclusion or discrimination, domestic violence and bullying. Others have particular affects at different stages of our lives - during childhood, young adulthood or when we are older. The following paragraphs highlight some of these.

Poverty

8. Northern Ireland experiences higher levels of deprivation than Britain or Europe.[5] The proportion of people on social security benefits here is higher than in Britain. One of the major causes of poverty and deprivation for families here is unemployment. The proportion of unemployed males who are long-term unemployed 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%[6].

9. Poverty, low wages, unemployment, poor housing and poor education have a substantial impact on people's health. Economic or financial disadvantage increases stresses, including everyday pressures to pay bills or to purchase food and clothing. It limits access to activities which enhance independence and wellbeing. There is evidence that people who are socially or economically disadvantaged may not readily report mental health complaints to health care workers.

The Conflict

10. The impact of the conflict on different communities was acknowledged in the report "Living with the Trauma of the Troubles"[7]. Residential segregation, population movement and displacement, the stigmatisation of certain neighbourhoods, bereavement and traumatisation all have negative effects on mental health. 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[8]. The Victim's Strategy[9] also acknowledges the psychological difficulties faced by victims of the conflict.

Rural Areas

11. 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.

Physical Factors

12. Northern Ireland has the highest prevalence of disability in the UK (17.4% compared to 14.2% in Great Britain)[10]. Chronic medical conditions and physical and sensory disability can lead to depression, anxiety, isolation and substance misuse. Sensory loss and the greater likelihood of illness and disability make older people

especially vulnerable to mental health problems. Physical disability can also have a negative impact on the mental health of parents and siblings.

Carers

13. Caring for someone can be physically, emotionally and financially draining. 65% of carers admit that their own health has suffered. Many are pensioners themselves and some are children who are taking on inappropriate levels of caring responsibility. Carers often feel isolated, unsupported and alone.

Factors Affecting Children

14. The formation and maturation of close relationship bonds is a critical part of child and adolescent development. When there is a failure to develop appropriate attachments, or where there is disruption of these relationships through separation, death or family break up, mental health problems may result. Children are at particularly high risk of mental health problems when there are distortions in relationships such as through physical or emotional neglect, or through physical, sexual or emotional abuse or bullying.

Factors Affecting Young People

15. There is evidence that boys enjoy less emotional support than girls. Greater personal isolation during teenage years may make boys and young men more vulnerable to mental health problems.

16. Research indicates that adolescents who reside in areas with low socio-economic status tend to perceive their neighbourhood as more dangerous than those in high socio-economic status areas. There is a direct relationship between the degree to which an area is perceived to be dangerous and threatening and reported levels of depressive symptoms, anxiety and conduct disorder[11].

Factors Affecting Adults

17. Research evidence suggests that men do not have such strong peer/external support mechanisms as women for coping with bereavement, emotional issues, abuse, stress and depression. This difficulty is reportedly compounded because many men are not experienced at asking for help, may not perceive their problems to be serious, and may be less willing to consult services.

18. For women factors such as abortion, the psychological impact of giving birth, having young children, post-natal depression and the menopause have important associations with mental health problems.

Factors Affecting Older People

19. Adjustment problems and socio-economic difficulties associated with retirement constitute significant risk factors for emotional distress in older people.

20. Various factors contribute to social isolation and increased risk of mental health problems. These include a decline in social activity; deaths of friends and relatives; transportation and mobility problems; less support due to smaller family size and living alone.

ANNEX 2

EFFECTIVE MENTAL AND EMOTIONAL HEALTH PROMOTION

ANNEX 2
EFFECTIVE MENTAL AND EMOTIONAL HEALTH PROMOTION

1. Effective promotion of mental and emotional health aims to meet the needs of:

   - **the well population;** and
   - **the 'at risk' population.**

2. Mental health promotion is most effective when Departments and Agencies work together to provide information and support. The messages can be reinforced in a wide range of settings including the media, the workplace, primary care, schools, libraries, places of worship, leisure centres and other community settings.

3. Approaches which have proved to be effective include:

   - promoting good social relationships, for example, through training for social skills, assertiveness, communication and relationships;
   - developing effective coping skills, for example, problem solving and parenting;
   - providing social support, for example, home visits from health workers to support new parents, supporting bereaved families;
   - policy development, for example, tackling bullying in schools and workplace harrassment.

4. Physical activity, either alone or as part of organised programmes, can improve emotional wellbeing. It can also prevent the onset of mental health problems and improve the quality of life for people with such problems.

5. Mass media campaigns can increase awareness of mental health issues and reduce the stigma associated with them. They can also be used to increase knowledge of how to cope with difficult circumstances and to identify sources of help and support.

6. Effective interventions will also take account of the specific needs of minority ethnic groups and people with disabilities. For example, the mental health needs of people with a learning disability can often be overlooked or attributed to their other identified difficulties; and deaf children who have limited access to the kinds of incidental hearing that support the development of social understanding may need particular support and help to build confidence and develop problem solving skills.

Children

7. Since childhood mental distress is strongly predictive of poor mental health and social outcomes in adult life, preventive interventions for children have clear potential to bring long-term psychological, social and economic benefits.

8. Effective interventions for children from disadvantaged communities and high risk families/children include:

   - high quality pre-school and nursery education;
   - support visits for new parents; and
   - home based programmes to strengthen the relationship between the child, parent or care giver.

Young People

9. A number of effective school-based programmes have been developed and evaluated. These are characterised by:

   - focusing on improving social skills;
   - reducing substance misuse and aggressive behaviour;
   - developing coping skills to deal with life situations.

10. Participation in creative arts has also proved to benefit young people experiencing personal, social and behavioural problems.

11. Research has shown that both being a bully or a victim of bullying is a good predictor for later problems[12]. Effective anti-bullying schemes involving the whole school have been shown to be effective and have significant long term impacts on criminal behaviour, alcohol misuse, depression and suicidal behaviour.

Adults

12. There is a range of effective interventions to promote the mental wellbeing of adults. These include:

   - general health promotion programmes involving the whole community in a participatory manner on healthy living;
   - community based support groups for the mildly depressed, divorced or separated people, unemployed, carers and recently bereaved people;
   - home visiting programmes focusing on parenting skills and specific interventions to reduce postnatal depression;
   - positive working conditions, including increased control at work, greater social support and pre-retirement interventions.

13. Brief interventions, such as simple advice, have proved to be effective in reducing excessive alcohol consumption. More severe alcohol related problems can be reduced by approaches which focus on skilled or specialist help, for example, in primary care services, addiction services or self help groups.

ANNEX 3

SUICIDE PREVENTION

ANNEX 3
SUICIDE PREVENTION

SUICIDE PREVENTION

1. Suicide, may be seen as an extreme result of poor mental and emotional health. Many of the contributory risk factors are common with those discussed in Annex 1. This Annex complements and reinforces Annexes 1 and 2.

2. Concern has been expressed that the incidence of suicide, especially among young men, may be increasing. However, it should be noted that there are difficulties in the formal recording of suicide. A commonly accepted definition for data collection purposes has not yet been developed.

3. The traumatic impact of suicide on families, relatives, friends and communities warrants a specific focus by those involved in promoting mental health and emotional wellbeing.

Primary Risk Factors

4. There is an acknowledged relationship between mental illness and suicide. The Report - Safety First: National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (2001) - reported the following findings in relation to suicide by people in Northern Ireland with a mental illness:

   - 79% of all suicides were male;

   - 50% were aged 39 years or under;

   - 71% were single, divorced/separated or widowed;

   - 60% were either unemployed or long-term sick; and

   - 34% lived alone.

5. The commonest diagnoses were depression, alcohol dependence, schizophrenia and personality disorder.

6. Other risk factors include combined alcohol and drug misuse, hopelessness, previous suicide attempt, low self esteem, unemployment, childhood neglect or abuse, bereavement, parental death during childhood, break-up of a relationship, social isolation, being unmarried and living alone.

Prison

7. Prisoners are in a vulnerable position and at higher risk of committing suicide.

Prevention of Suicide

8. While no specific intervention has been found to be universally effective, these risk factors must be addressed as part of a broader approach to mental and emotional health. Preventive measures include: reducing access to the means of suicide; promoting coping skills in

the general population; targeted work with vulnerable groups; well managed and responsive health and social services which can recognise mental problems early and make timely interventions.

9. Specific actions which may contribute to the prevention of suicide include:

- early identification of mental or emotional distress;
- immediate access to sources of support and treatment especially for depression;
- support for individuals and families after a suicide has occurred;
- information and research into the complex interaction of risk factors and precipitating events that may lead on to a suicide.

These actions can be tackled through a wide range of settings and sectors.

ANNEX 4

EQUALITY IMPLICATIONS

ANNEX 4
EQUALITY IMPLICATIONS

1. Introduction

Northern Ireland Act 1998

1.1 Section 75 of the Northern Ireland Act 1998 requires the Department of Health, Social Services and Public Safety (DHSSPS) in carrying out its functions relating to Northern Ireland, to have due regard to the need to promote equality of opportunity –

- between persons of different religious belief, political opinion, racial 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.

1.2 In addition, without prejudice to the above obligation, DHSSPS should also, 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.

Background

1.3 Mental health problems are one of the most common forms of ill health. Approximately 1 in 6 adults will at any one point in time, have a diagnosed condition such as depression or anxiety. In September 1998, DHSSPS commissioned the Health Promotion Agency to lead and facilitate a regional multi-disciplinary Task Force to develop a Strategy and Action Plan for mental health promotion with targets for implementation. The terms of reference were:

> “The Strategy and Action Plan should address issues which affect mental health; it should have a mental health rather than a mental illness focus and should aim to cover the needs of individuals and communities, not just those with existing mental health problems. It should also aim to increase understanding about mental health, develop education programmes and plan a media strategy to support the framework.
>
> The Strategy and Action Plan should focus on the differing needs of children, young people, adults and elderly people and identify groups, within each of these age ranges, which might benefit from specific intervention to promote good mental health and wellbeing.
>
> It should specifically address the problems associated with suicides particularly among young people and include measures to help young people develop a positive self-image and healthy and satisfying relationship with peers and family.”

1.4 Following consultation and discussion with a wide range of interested organisations a draft Strategy "Minding our Health" was published for consultation in April 2000. Given DHSSPS's commitment to promote equality of opportunity and good relations the consultation invited views on the extent to which the draft Strategy was consistent with these principles.

1.5 Responses were received from 38 organisations and individuals. The majority of responses were generally favourable and considered that the terms of reference had been met. With regard to equality some responses considered that more specific recognition needed to be given to the needs of vulnerable people such as homeless, minority ethnic groups, disabled people and postnatal women. These responses have been taken into account in the further development of the Strategy and Action Plan.

2. Aims of the Strategy and Action Plan

2.1 The aims of the Mental Health Promotion Strategy and Action Plan are to improve the mental and emotional wellbeing of the general public, particularly those at risk or more vulnerable and those with identified mental health problems, their carers and families. It also aims to prevent, or reduce the incidence and impact of, mental and emotional distress, anxiety, illness and suicide, raise awareness of mental and emotional health at public, professional and policy making levels, and reduce discrimination against people with mental health problems.

2.2 The policy has been defined by DHSSPS. It will be implemented by DHSSPS and its agencies in conjunction with other Departments, statutory bodies and the voluntary and community sectors.

2.3 The policy will increase awareness and understanding of mental health issues, address inequalities by targeting vulnerable groups, and ensure that those with continuing mental health problems have access to the same opportunities as others in the community. The outcome of the policy is to prevent and reduce the number of people with mental ill health, reduce discrimination, promote early intervention in mental health problems and reduce the number of suicides.

3. Groups Affected by the Policy

3.1 The policy will affect the health and wellbeing of the population generally. It will therefore affect all of the Groups listed in 1.1.

4. Consideration of Available Data and Research

4.1 When considering the equality implications of the Strategy and Action Plan account was taken of information provided by existing surveys and also information through discussion with voluntary organisations as set out below.

i. Source: Health and Social Wellbeing Survey 2001

Results indicate that a greater proportion of the population is at an increased risk of mental ill health when compared to England and Scotland. These were people who had a score 4 and above when assessed using the twelve questions of GHQ 12 (General Health Questionnaire 12) which indicates the possible presence of psychiatric disorder. In Northern Ireland 17% of men and 24% of women reached this threshold compared with 13% of men and 18% of women in England and Scotland.

Marital Status – 19% of people who are married and living with their partners showed signs of a possible mental health problem compared to 33% who are divorced.

Respondents who were divorced were over twice as likely to have experienced a great deal of worry or stress (23%) compared with those who are married and living with their partners (11%).

Religion – 19% of Protestants showed signs of a possible mental health problem compared with 23% of Catholics.

12% of Catholics and 11% of Protestants experienced a great deal of worry or stress in the previous twelve months.

Gender – 17% of men and 24% of women showed possible signs of a mental health problem. Women in most age groups with the exception of those aged 55-64 years were more likely than men to show signs of mental health problems.

Women were more likely to have experienced a great deal of worry or stress than men, 14% compared with 10%.

ii. Source: 1997/98 Health Behaviour of School Children

Gender/age - one quarter of all pupils surveyed (24.9%) had experienced bullying, for 60% of this group it had occurred only once or twice.

Boys are more likely to be bullied than girls.

Younger children are more likely to report being bullied.

Almost one in five (19.8%) of the survey group admitted to having taken part in bullying, only 1.2% admitted to frequently bullying others. Those who have been bullied themselves are more likely to bully others.

FREQUENCY OF BULLYING BY THOSE WHO HAVE BEEN BULLIED THEMSELVES

	Never been bullied (%)	Been bullied sometimes (%)	Been bullied frequently (%)
Bullied others frequently	1.1	2.2	11.0

27.7% of the survey group said they felt pressured by schoolwork - 10% said they felt under a lot of pressure.

The proportion of young people who feel pressured increases as they get older. There is a large increase in the number of both boys and girls reporting they felt under pressure in year 12 (GCSE year) – in primary 7 less than 1 in 10 felt stress while in year 12 over 1 in 4 reported stress.

iii. Source: National Deaf Children's Society

Disability/Age - deaf children are more likely to be impulsive, with limited social problem solving skills, and greater difficulty in identifying and naming their own and other people's emotional states (Kusche and Greenburg 1987). Deaf children are at greater risk of developing mental health problems than their hearing peers (Hindley, Hill, McGuigan and Kitson 1994).

iv. Source: Birkett, S and Foyle Friend, "The Experiences of Lesbian, Gay and Bisexual People at School in the North West of Ireland"

75% of gay men experienced homophobic bullying at school.

v. Source: White, RG, McCracken, A., and the Rainbow Project, How Hard Can It Be?: Attempted Suicide of Gay Men - the Psychological Stressors and Associated Risk Factors, Rainbow Project, 1999

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.

48% of those who had been sexually assaulted considered committing suicide.

vi. Source: Toner, F., McCracken, A., McIlwrath, K., and the Rainbow Project, Express Yourself!: An Investigation into the Counselling Needs of Gay Men in Northern Ireland, Rainbow Project, Belfast, 1999

61% of gay men reported suffering emotional abuse from school mates.

vii. Source: Safety First: National Confidential Inquiry into suicide and homicide by people with mental illness (2001)

From April 1997 – April 2000 there were 502 notified suicides and probable suicides in Northern Ireland. Of the 502:

Gender - 79% were male;

Age - 50% were 39 years or under, 7% were over 65 years;

Marital Status - 71% were single, divorced/separated or widowed.

There was no information on religion, political opinion, racial group, disability, sexual orientation and persons with dependents and persons without.

5. Assessment of Impact

5.1 The policy aims to promote the mental health and wellbeing of the population generally as well as those at risk. Responses to the consultation on "Minding our Health" identified certain groups at risk – post natal women, young men and women, ethnic minorities, Travellers, people with learning disability and deaf children. They also highlighted the need for appropriate training such as disability awareness and the need for accessible information for ethnic minority groups and disabled people.

5.2 Consideration of the data in paragraph 4 indicates that women, divorced people and Catholics are more likely to have poor mental health, boys are more likely than girls to be bullied and men are more likely to commit suicide than women. Discussions with voluntary organisations have also highlighted issues around sexual orientation and deafness.

5.3 DHSSPS recognises that all of these groups have particular needs and professionals in the areas of health, social services and education need to be aware of these needs and have the knowledge and skills to deal with them. The Strategy and Action Plan has been developed with this in mind and it is the DHSSPS view that it should not have an adverse impact on any of the groups. It should promote equality of opportunity by ensuring that professionals receive relevant training and skills and are aware of the particular needs of different groups, and that the groups have access to accessible information and services.

6 Monitoring of Impact

6.1 An Implementation Group is to be established to take forward the Strategy and Action Plan. This Group will advise on a research programme and report progress on an annual basis to the Ministerial Group on Public Health. Surveys will be used to monitor progress. In addition the DHSSPS regularly meets voluntary organisations and will use these opportunities to monitor progress and identify any adverse impacts of implementation of the Strategy and Action Plan.

REFERENCES

REFERENCES

1. The Health and Social Wellbeing Survey 2001.

2. Making it Happen Health – A Guide to Delivering Mental Health Promotion. Department of Health, 2001.

3. Minding Our Health - A Draft Strategy for Promoting Mental and Emotional Health in Northern Ireland.

4. Health Education Authority. Community Action for Mental Health. London: HEA, 1998.

5. The Family Expenditure Survey Report for Northern Ireland 1998/99.

6. Labour Market Statistics. Northern Ireland Statistics & Research Agency and Office for National Statistics, July 2002.

7. Social Services Inspectorate. Living with the Trauma of the Troubles. Belfast: Department of Health and Social Services, 1998.

8. The Cost of the Troubles Study. Report on the Northern Ireland Survey: the experience and impact of the Troubles (1999), Fay,M.T., Smyth, M and Wong,T. NICORE (University of Ulster and the United Nations University) Londonderry.

9. "Reshape, Rebuild, Achieve" Delivering Practical Help and Services to Victims of the Conflict in Northern Ireland. Office of the First Minister and Deputy First Minister, April 2002.

10. PPRU Surveys of Disability.

11. Aneshensel C S and Sucoff C A. The Neighbourhood Context of Adolescent Mental Health. Journal of Health and Social Behaviour, 1996; 37: 293-310.

12. Olweus, Don. Bullying at School: What we know and what we can do. London: Blackwell, 1993.

NOTES

Independent Review of Health and Social Care Services in Northern Ireland

Article · January 2005

John Appleby

Independent Review of Health and Social Care Services in Northern Ireland

Professor John Appleby

August 2005

Contents

Executive summary

Dear Minister

In late 2004, I was asked by the then Northern Ireland Finance Minister, Ian Pearson, with the support of the Health and Social Services Minister, Angela Smith to conduct a Review into the provision of Health & Social Care Services in Northern Ireland. The Terms of Reference for the Review set out in Annex A are broadly similar to those for previous studies carried out by Derek Wanless into the health & social care sector in Wales and the UK as a whole.

The main objective of the Review was to examine the likely future resource requirements of the health & social care sector in Northern Ireland. I was also asked to consider the scope for the resources devoted to health & social care to be used more effectively. A particular area of concern was the lack of progress on waiting times despite significant additional resources. This was linked to the apparent inability to track funding through the system .

The Review began in January 2005 with a series of meetings with patient and staff representatives as well as community and voluntary groups, and local political parties. Meetings were also held with senior managers and departmental officials. Overall, the Review has been in contact with around 100 individuals from over 40 organisations. In these meetings I was struck by the desire to provide the best possible care to the people of Northern Ireland, but concern that this was being hindered by weaknesses in the system. There was a real openness for reform which, although evident in some specific areas, was not being driven forward on a widespread basis. The general perception was that political instability and a lack of leadership throughout the system had created an unstable environment where it took too long for decisions to be made and which in turn were too easily obstructed from being implemented by narrow local concerns.

As part of the Review I commissioned a survey of a sample of the Northern Ireland’s population’s health status , whilst GPs and the Chief Executives of health & social care trusts were also surveyed to garner their views on the management of waiting lists. However, given the short amount of time in which the Review was to be completed we relied heavily on existing data sources and policy documents. External expertise was sought in certain areas and I am most grateful to the Informal Reference Group of health policy academics for their advice and comments on the progress of the Review.

The Review covered a lot of ground and drew on extensive data - reflected in the length of this report. Three areas were dominant, however: Funding, the use of resources and the performance management system and findings in these areas are summarised below together with a number of recommendations for your consideration.

Funding

In common with the rest of the UK, significant additional resources have been devoted to the provision of health & social care in Northern Ireland in recent years. However, the short-term and uncertain basis on which funds have often been allocated has hampered the strategic planning of services. Around three-fifths of the additional funding has been absorbed by increases in staff costs, reflecting the labour intensive nature of the sector, although most of this has been in higher wages and salaries rather than more frontline staff. Whilst it is estimated that around a quarter of the additional funds have been spent on service delivery improvements, looking forward, cost pressures (such funding required to implement Agenda for Change and the new GP and consultants' contracts) mean that a much smaller share of future funds will be available for service improvements.

Despite the concerns of Ministers, it has been possible to track the additional resources allocated to the health & social care sector in recent years from a range of perspectives. However, whilst the linkage between Budget bids agreed by Ministers and actual out-turn expenditure was relatively clear for hospital services, it was less obvious with respect to community and social services. Although DHSSPS have taken steps to ensure stricter adherence to funding decisions there is also a need for sufficient flexibility to allow service providers to respond to local needs where appropriate.

> **Recommendation 1: In the light of suggested future funding (see Recommendation 3), in-year monitoring additions to health and social care budgets should cease other than in exceptional circumstances and solely on a one-off basis (Section 2.2.2).**
>
> **Recommendation 2 : Over and above the need to track spending for reasons of financial probity, the main performance policy monitoring focus should be on tracking outcomes, not spending per se. A programme budgeting approach - as currently being developed in England for 23 disease/service groups- in addition to traditional accounting would be of help with this (Section 2.2.3).**

In terms of future funding, the trends determining resource requirements in Northern Ireland are expected to be similar to those in the rest of the UK. Although an ageing population is likely to increase the demand for resources, changes in public expectations and in particular technological developments will have an even greater impact. On the other hand, improvements in public health behaviour such as smoking and diet will tend to reduce requirements, whilst increases in productivity will allow more to be delivered for a given level of resources.

In order to quantify future resource requirements we adopted the most straightforward approach of estimating Northern Ireland's appropriate share of the expenditure projections for the UK as a whole set out by Derek Wanless. Northern Ireland is currently funded on the basis of its population share of increases in spend in England by the operation of the Barnett Formula. However, this simplistic mechanism does not take into account the differences in the need for health & social care expenditure between Northern Ireland and England.

There have been a number of models developed to inform the allocation of funds between and within UK countries on the basis of need. However, the main focus of this Review has been on the HM Treasury Needs Assessment Model (NAS), and the subsequent methodological revisions to this model suggested by the Northern Ireland Executive in 2002. The main revision was to increase the importance of deprivation in estimating the relative need for health & social care expenditure. The overall impact of these revisions is to increase the relative need for health & social care spend in Northern Ireland from 4% higher than England per head of population to 13% higher. The respective formulae for allocating funds *within* Northern Ireland and England were also adapted to allow a cross country need relativity to be calculated as a further comparison. Whilst the results tended towards those of the Northern Ireland Executive revised NAS model, they were highly sensitive to changes in the assumptions underlying key factors. In addition, the results from using the original Treasury model are consistent with the results of the survey of health status which is considered to be a better direct measure of the need for health expenditure than the proxy type variables used in the NAS model.

Having considered the evidence base for the revisions and taken expert advice I have come to the conclusion that whilst neither model is without fault, the weight of evidence is not yet sufficiently robust for the Northern Ireland Executive revisions to be accepted by HM Treasury as the final arbiter in this respect. The judgement of this Review (to be confirmed or denied in the light of any subsequent results arising from a UK-wide allocation model) is that a reasonable need differential between England and Northern Ireland should be around 7%. The expenditure projections for the Northern Ireland health & social care sector set out below, based on a 7% higher level of need, suggest that a significant increase in resources is required in the coming years, but with slower growth thereafter.

Table 1: Health And Social Care Spending Projections for Northern Ireland

	2002-03	2007-08	2012-13	2017-18	2022-23
Total NI Health & Social Care Spending (£ billion 2004-05 prices)					
Solid Progress	2.7	3.7	4.7	5.5	6.2
Slow Uptake	2.7	3.8	4.9	6.0	7.1
Fully Engaged	2.7	3.7	4.6	5.3	6.0
Average annual real growth in NI Health and Social Care spending (per cent)					
Solid Progress		6.8	4.6	3.1	2.7
Slow Uptake		7.0	5.4	4.0	3.5
Fully Engaged		6.8	4.3	2.8	2.4

A key issue, however, is whether the 7% greater level of health & social care spending should come from other spending areas within Northern Ireland (including efficiency improvements from within health and social care services) or from additional allocations from HM Treasury. Given that health & social care accounts for over 40% of Government spend in Northern Ireland and the likelihood is that other areas of spend in Northern Ireland will have a higher need for spend than in England, it will be unsustainable for the additional resources for health & social care to be entirely sourced from within Northern Ireland.

Recommendation 3: Adopt HMT NAS model-based Wanless 'fully engaged scenario' projections as set out in Table 1 for now as best reasonable guide to future spending in NI (Section 2.3.4).

Recommendation 4: Further work is needed to investigate the usefulness of employing direct measures of health status (for example, as derived from instruments such as the EQ-5D) in resource allocation models (Section 2.3.4).

Recommendation 5: Future work on pan-UK resource allocation model would provide a more empirically-based answer to relative shares of resources. Such work should be open, and draw on extensive experience in the area of resource allocation models of research groups across the UK (Section 2.3.4).

Recommendation 6: If the future spending path suggested by this Review is accepted, then there needs to be some way round the implications of the Barnett Formula for health and social care if the general principle of Barnett are to be maintained and other public services in Northern Ireland are not to suffer (Section 2.3.5).

Use of resources

In addition to extra funding, it is critical that the resources available to the health & social care sector are used as efficiently as possible. As there is no single measure available that would allow a comprehensive comparison of performance both within Northern Ireland and with other countries, the Review considered a range of efficiency and productivity indicators.

Overall, health status in Northern Ireland as measured by the EQ-5D survey was found to be slightly worse than in the rest of the UK - linked to poorer diets, heavy smoking, lack of exercise and other lifestyle and environmental causes. As a result, hospital activity tends to be higher than in England. However, there appeared to be a number of areas where health care utilisation was substantially higher than health status would suggest, such as accident and emergency attendances, which are almost a third higher than in England.

Recommendation 7: Routine collection of self-assessed health status data at population level would yield useful comparative data on population health status. In addition, the potential for routine collection of patient related outcome measures in health care services should be explored (Section 3.2).

Recommendation 8: On the basis of current lifestyle data, the funding recommendations based on the Wanless 'fully engaged' scenario imply considerable effort will be needed to engage the Northern Ireland population through expanded public health services and other means (Section 3.2).

Recommendation 9: Further investigation is required of very high A&E use to explore reasons and find ways for reducing likely inappropriate use (Section 3.3.1).

Recommendation10 : Detailed analysis is needed into hospital activity trends as part of a broader analysis of the dynamics of waiting times and lists (Section 3.3.1).

Recommendation 11: DHSSPS should develop a more coherent strategy towards partnership with private sector (Section 3.3.2).

The most obvious indication of poor performance has been the large number of people on waiting lists and waiting times for treatment compared with the rest of the UK. Whilst there has been some limited progress in terms of inpatient waits, there continues to be an upward trend in the number of people waiting for outpatient appointments.

The main focus of analysis was on the extent to which there is variation in performance between trusts and specialties. Whilst significant variation would reflect avoidable underperformance, it would also highlight the scope for improvement. It was found that the overall Northern Ireland waiting list is accounted for by a small number of trusts and specialties. There are also significant differences in performance over time, with some trusts able to reduce the number of long waiters whilst others have not.

One common approach to the problem has been to set targets (coupled with rewards and sanctions) for reductions in waiting lists and waiting times - a strategy which arguably has been the key factor in driving down waiting times in England over the last few years. However, in Northern Ireland while targets have been set, very few have been met, whilst the target setting process has been somewhat erratic with few apparent long-term goals and intermediate milestones, and noticeable gaps in target setting, such as outpatients. However, there are some good examples where trusts have tackled the problem of waiting often using examples from the Modernisation Agency. The critical role of Northern Ireland GP’s in managing the initial flow of patients into hospitals needs to be considered in greater detail than that which has been possible for this Review,

From our survey of GPs one of the main perceptions for the lack of progress in this area is the lack of a consistent commitment throughout the health & social care system to reducing waiting times, as well as the lack of incentives or sanctions in order to drive the effort to meet the targets. Overall, the conclusion of this Review is that excessive waiting is not inevitable, nor an intractable problem given the level of financial inputs to the system. Solutions to the problem require a “whole systems” perspective, involving all parts of the health & social care system, and with consistent commitment to reductions from the highest levels of management.

In practice, tackling excessive waiting will involve most if not all of the following:

- Efficient use of key resources
- Weekly monitoring of lists by chief executives
- Continual validation of lists

- Treat-in-turn, together with consistent urgency prioritisation
- Clear bottlenecks (e.g. bed blocking, ringfence elective beds)
- Set targets coupled with incentives/sanctions (for individuals and organisations)
- Manage the entire patient pathway - from GP to outpatient to diagnostic services to waiting list to admission to discharge.
- Publish performance data (by hospital, specialty and clinical team).
- Reduce variations through patient choice
- Contain and if possible reduce, other demands on the hospital system - especially accident and emergency attendances and emergency admissions.

Whilst the recent announcement by Shaun Woodward to introduce the Second Offer Scheme is welcome given its success in Wales in reducing Inpatient and day case waiting times, it will be important that care is taken in terms of the detail of how this scheme is to be implemented. In particular, that the second offer treatments still represent value for money whilst the Tier 2 Outpatient Services should not simply be a vehicle to keep those still waiting for treatment to be completed off the formal waiting lists.

Recommendation 12: Adopt a multi-pronged long term strategy to reducing waiting times, including long term targets (with milestones) backed by strong incentives (Section 3.6.8).

Whilst excessive waits for treatment can be the result of high levels of demand (which in itself may reflect inefficiency in other parts of the system), the extent to which services are delivered effectively is a factor that too often has been ignored, with debate focusing on the amount of resources available. The Review considered a range of performance indicators on this matter. Whilst all have their weaknesses, collectively they present a broad indication of overall performance. Our main findings were:

- Hospital activity per member of staff is 19% **lower** than the UK average.
- Hospital activity per pound of health spend is 9% **lower** than the UK average
- Hospital activity per available bed is 26% **lower** than in England
- The unit cost of procedures is 9% **higher** in NI than England with day case unit costs 9% **lower** and elective inpatient unit costs 12.6% **higher**.
- There are significant variations in unit costs between trusts
- Day case rates are **higher** than the UK average and have risen significantly since 1990/91.
- Length of stay has remained broadly unchanged over the past five years.
- Average unit prescribing costs are nearly 30% **higher** in Northern Ireland than in England

Overall, the picture that emerges is one of fewer outputs achieved per given level of input than in England, although some aspects of poor performance are shared with Scotland and Wales. Whilst there are a number of potential explanations for this in addition to simple inefficiency (such as better quality of provision, maintaining hospitals in rural locations, and higher costs of delivering services in deprived areas) it still needs to be recognised that such performance differences represent additional costs on the system that could be used to increase activity and address problems such as waiting lists.

Recommendation 13: Investigate ways to reduce unit cost variations through incentive mechanisms such as tariff-based activity payment/budget setting systems (Section 3.7)

Recommendation 14: Further investigation is needed to explore possible of reasons for high unit costs at the Royal and Green Park Trusts (Section 3.7).

Recommendation 15: Investigate scope for further reductions in length of stay and avoidance of admission to hospital (Section 3.7)

Recommendation 16: Aim in medium term to use outcome-based productivity measures (Section 3.7).

Although the main focus of this Review has been on hospitals, this is not to diminish the vital role of family and social services. Although GP list sizes are smaller in Northern Ireland, the number of consultations per head of population is higher. There appears to be a lack of integration between GPs and the rest of the primary care sector which needs to be improved through a change in attitude on both sides. In addition, it is not clear that the new payments contract for GPs represents good value for money. In terms of prescriptions, despite implementing various initiatives to reduce the problem, Northern Ireland still has a significantly higher level of spend on prescription drugs per head of population than the rest of the UK. As with the rest of the health & social care sector this can be linked in part to the absence of sanctions to discourage poor performance.

Recommendation 17: An assessment should be carried out on the implementation of the GMS contract in Northern Ireland to examine whether the actual improvements in quality outweigh the cost. In light of the finding, the GMS contract should be revised as far as practicable (Section 3.4)

Recommendation 18: New mechanisms involving greater use of sanctions are needed to tackle high prescribing costs and to encourage greater use of generic drugs (Section 3.4).

Social services is the area of the health & social care system where provision in Northern Ireland is considered to be the furthest behind that in England. Whilst the available evidence suggests that this is not necessarily the case, Northern Ireland still appears to be many years behind in England in terms of achieving the policy aim of providing social services in a community rather than hospital environment wherever possible. In addition, despite having lower unit costs than in England, there appears to be scope for services to be delivered more efficiently. Independent/voluntary organisations, which rely on the public sector for funding, but are also in competition in providing services and for resources, highlighted a number of aspects where the relationship with Government could improve.

Recommendation 19: The integration of health & social services should be re-examined with an initial first stage being the implications of ring fencing of funding for social services from the acute sector. There should however be scope for financial sanctions when inefficiency in one part of

the system impacts negatively on another e.g. lack of social services provision causing delayed discharge from hospital (Section 3.5).

Recommendation 20: Contracting for services from independent/voluntary organisations should be reviewed to consider whether it can be placed on a more strategic basis (Section 3.5).

A key element in the efficient delivery of services is the recruitment, retention and motivation of staff. Whilst there was concern expressed about staff shortages, Northern Ireland does not appear to be deficient in terms of the number of health & social care staff compared to the rest of the UK. In addition, in common with the rest of the UK, labour productivity in the health & social care sector appears to have fallen since 1998/99. The main impetus to improve productivity in the UK as a whole has been the Agenda for Changes pay reforms as well as changes to consultants' and GP contracts. However, there is little evidence so far that this will have a significant impact on productivity despite the additional cost involved.

An additional issue in Northern Ireland has been the Government's policy on local pay flexibility for public sector workers given that most health & social care staff groups follow national pay settlements despite not being part of the respective pay review bodies. In assessing the case for maintaining the current position, the Review found that the public sector pay premium for health care workers was larger in Northern Ireland than the rest of the UK, whilst the cost of living is significantly lower, Long-term vacancies rates were also lower, as was reliance on international staff, whilst there appeared to be relatively little problem in terms of recruitment. Therefore, there is a case for the argument that the main reason for past and predicted labour shortages being an insufficient number of training places rather than the level of pay.

Recommendation 21: Further investigation is required of possible reasons for relatively low labour productivity (Section 3.8.3)

Recommendation 22: Health and social care workers in Northern Ireland should formally come under the remit of the relevant GB Pay Review Bodies: this will enable the Government's local pay policy to be implemented on an equal basis in Northern Ireland to the rest of the UK (Section 3.8.4).

Performance management

Finally, of critical importance is the effectiveness of performance management arrangements to drive the system forward to improve efficiency, effectiveness and responsiveness.

The impression I have gained over the course of this Review is of a system lacking urgency, of general drift, and a consequent frustration amongst many in the services - at all levels - with the relative lack of improvement in performance.

Current performance management arrangements lack appropriate performance structures, information and clear and effective incentives - rewards and sanctions - at individual, local and Northern Ireland organisational levels to encourage innovation and change.

The Review of Public Administration's recommendations for reconfiguring health and social care organisations - in particular, the creation of around five Health and Personal Social Services agencies - in effect reinvent a pre-1990 English NHS model in which health authorities received weighted capitation allocations, planned services and directly managed (and set budgets for) the hospital providers in their area. However, despite acknowledging that there *'must be clear lines of accountability to the Department and the Minister for expenditure, quality and performance*', and while noting that performance management remains the remit of the Department, it is not clear in this model how performance improvements are actually to be achieved. In particular, it remains to be seen how providers are to be held to account for their performance. While 'partnership and integration' can generate good things for patients and users, there is a distinct danger that the performance model implied by the RPA's structural reform could fail to provide the necessary incentives and sanctions - or 'bite' - to encourage providers of services to continually seek out new ways to improve their performance.

Overall, from the point of view of performance management, it is hard to see any difference between the RPA's recommendations and the way the current system operates.

In contrast, this Review would suggest that some form of separation between the providers of services and the funders/commissioners of services would be an important factor in sharpening up incentives in the system. Given the particular circumstances in Northern Ireland, its population size and distribution, the political governance structures etc, there needs to be further investigation of the most appropriate form of separation, however. While the four health boards have, in theory, acted as commissioner/purchasers, it is not clear that the full benefits of this arrangement have been achieved. It may be that a single pan-Northern Ireland commissioner would be more appropriate. This arrangement would not preclude some devolution of commissioning to GPs (see below). A crucial aspect of such arrangements however is the design of the rules of engagement and the framework in which commissioners are required to operate. In particular, commissioners would need clear objectives/targets in order to drive performance through their commissioning decisions. The regional level performance management system therefore needs to be reformed to take on serious, long term target setting

Moreover, the performance management system needs to be reformed to take on serious, long term target setting coupled with rewards and sanctions at organisational and individual levels and greater devolution to providers. In turn, providers themselves need to consider how to devolve functions within their organisations, in particular, ways in which to engage frontline staff with the incentives faced by the organisation as a whole - through, for example, devolution of budgets and associated responsibilities.

The nature of the rewards and sanctions need careful thought. The competitive economic environment - at least as it is currently being developed in England - is unlikely to be appropriate in Northern Ireland. However, this does not rule out, for example, the introduction of an activity-based prospective reimbursement system for providers (similar to Payment by Results) with tariff setting (not necessarily fixed at average costs) used to drive improvements in efficiency and selective increases in activity to meet pan-service goals. Nor does it rule out the promotion of greater public and patient awareness of variations in performance in the system. The recent Ministerial initiative on waiting lists is a welcome first step in this direction although implementation will be key.

Further, it does not rule out careful expansion of patient choice. While in England choice is being rolled out mainly with a policy emphasis on the leverage it may have over providers (crudely, losing business will stimulate cost and quality improvements), from the patient's point of view, a more formalised and embedded process of choice (not just of hospital, but over the myriad of decisions that are taken throughout the system which affect a patient's care) can improve patient satisfaction and service responsiveness. This may be a weaker incentive than that being introduced in England, but the limits to what could realistically be offered by way of choice need to be recognised in what is a relatively small system. Nevertheless, there may be certain services, specialties, operations etc where options do exist for real patient choice and where patients would like to exercise greater choice.

In addition, and despite the previous rejection of GP fundholding, ways of both strengthening the involvement of general practitioners in the system and as part of a devolution strategy for commissioning secondary care services, thought should be given to the practical involvement of GPs in the purchasing of care. Again, Northern Ireland has an opportunity to develop its own approach to this form of devolved commissioning.

Finally, no system relies on just one or two performance levers. In England, for example, the new payment system and (managed) patient choice are going to run alongside continued use of targets (renamed 'standards') and, importantly, an evolving regulatory system at arms length from government which aims to promote the ultimate goals of the system - better quality of care, more efficient and cost effective use of resources. NICE, the National Patients Safety Agency, the Healthcare Commission etc, are important organisations which aim to promote better care. Much of these organisations' work and output are public goods available for any system to use and from which Northern Ireland could benefit and could inform development of the new HPSS Regulation and Improvement Authority.

Recommendation 23: There is a need to develop an explicit performance management system with rewards and sanctions which provide enough 'bite' to encourage change and innovation in the health and social care system. There are many options for the types of incentives that could be introduced and their design for Northern Ireland. There should however be a commitment to such reform coupled with further investigation of how incentives can be strengthened (Section 4.3).

Recommendation 24: Separation of the tasks of service provision and commissioning is an important factor in sharpening incentives. However, the most appropriate structures (e.g. single pan-NI commissioner; devolved GP commissioning etc) needs further investigation (Section 4.3).

Recommendation 25: Alongside changes in the performance management system, there is a need to explore the development of a more transparent priority setting process at national level, together with an explicit ‘NHS Plan for Northern Ireland’ which sets out outcome-based targets linked to new spending paths (Section 4.3).

In conclusion, although the Northern Ireland health & social care sector does not appear to have been significantly under-resourced up until now, looking forward it will come under increasing pressure to replicate the improvements in health outcomes envisaged for the UK by Sir Derek Wanless - but without a significant increase in funding. Notwithstanding this, however, it is clear that a significant underlying reason for current problems with the Northern Ireland health & social care sector relate to the use of resources rather than the amount of resources available. There is considerable scope for improvement in the provision of services conditional on appropriate incentive structures being in place that focus on improving health outcomes, whilst recognising that more efficient delivery means more resources available for service improvements. Although the timeframe for the Review has meant that certain aspects such as capital investment have not been covered and others have not been considered in the detail that I would have preferred, I hope that this Report will set a more realistic context in which the future strategic direction of the Northern Ireland health & social care sector can be set.

John Appleby

Professor John Appleby
July 2005

1: Introduction

1.1 Background to this Review

This Review was commissioned in late 2004, by the then Northern Ireland Finance Minister, Ian Pearson, with the support of the Health and Social Services Minister, Angela Smith. The background to this Review was two-fold. First, a growing feeling that despite many years of significantly higher per capita health and social care spending than, in particular, England, Northern Ireland was not enjoying the levels of outputs and outcomes that might be expected even allowing for a greater level of need. Secondly, over the last few years a number of wide-ranging reviews have taken place in other parts of the UK, starting with the first Wanless Review of future funding for health care across the UK, and followed by a second Wanless Review investigating ways to improve the public's health. Further efficiency and organisational reviews have also been conducted in Wales (again, under the auspices of Sir Derek Wanless), and now, most recently, in Scotland - the Kerr Review.

While somewhat different in nature, each of these reviews has attempted to tackle some similar issues, not least, how to ensure that the scarce resources society agrees to make available to health and social care services generates the best outcomes for patients and other users.

This Review most closely resembles that carried out in Wales - where similar concerns were felt about the ability of the system to deliver given its financial inputs. Apart from tackling this efficiency question, this Review has also examined what the future might look like with respect to the level of funding that should be made available for health and social care services.

Over the next few years, across the UK, spending on health and social care will absorb one pound in every ten in the entire economy, taking the UK into the upper half of the spending league in comparison to similar countries. And as a public service, funded from taxation, where every extra pound spent on health and social care is a pound not spent on other public services, there is therefore a growing need (if not an absolute requirement) to explore how funds are used and whether there are better ways to achieve the goals set for health and social care services.

1.2 Terms of Reference[1]

The overall aim of the Review is to look at the resourcing of health and social services and to consider how reforms leading to targeted and sustainable investment, effective and efficient delivery structures and appropriate incentive systems can result in improved service delivery. The specific objectives of the Review are based on those previously undertaken in Wales and at the UK-wide level. The Review will need to consider and make recommendations in the following areas:

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[1] See Annex A

1. the current position in levels of demand in relation to the levels of funding available;
2. the demands of the population for health and social services in NI, taking account of its distinctive characteristics, in terms of long term and sustainable resourcing;
3. technological, demographic, medical and other trends over the next two decades that may have implications for the future resource needs of the HPSS sector in NI consistent, where possible, with the approach adopted in the Wanless Review;
4. the extent to which resources are being used effectively and efficiently and, if there is evidence of sub-optimal resource utilisation, the issues which are impairing the most efficient and effective use of resources;
5. the scope for a more effective use of resources (human, revenue and capital) to bring about a significant improvement in access to, and quality of, services in the HPSS and specifically the optimum balance between prevention, community-based care and acute hospital care;
6. ways in which the interactions between the health and social care systems can be improved to maximise performance and the use of resources
7. the effectiveness of the organisational and incentive structures, decision-making and accountability processes in health and social care in NI;
8. further measures to improve health and well-being which can reduce the demand for health and social services.

1.3 Methodology

The Review will need to consider the present distribution of resources and the outcomes achieved for the level of spend. Performance measures and indicators will be an important part of the issues to be taken into consideration, and the establishment of incentives to encourage best practice. The Review will take evidence from key stakeholders with a focus on gathering evidence of best practice and what works.

1.4 Structure of report

Section 2 of this report examines historic and current funding levels in Northern Ireland, tracks current spending from various perspectives and, importantly, adapts the approach and results employed by the first Wanless Review of future funding in the UK to suggest possible spending paths for health and social care services in Northern Ireland.

Section 3 then provides more in-depth analysis broadly bearing on the question of the efficiency with which services are currently delivered in Northern Ireland. This section focuses on the level of use of and activity provided by health and social care services, waiting lists and times, efficiency of provision and issues concerning workforce and pay.

Section 4 examines the current performance management arrangements in Northern Ireland, and suggests how these might be strengthened in order to improve performance.

1.5 Acknowledgements

This Review would not have been possible without important contributions from many people. In particular, I would like to thank the Chief Economic Adviser of the Northern Ireland Civil Service, Michael Brennan and his team for their analytical support and Sarah Benton for secretarial support to the Review.

Support also came from the DHSSPS in providing data, analysis and answers to our questions. In particular I would like to thank Denis McMahon - our main link with the DHSSPS, Clive Gowdy and Paul Simpson and their staff, with Michael McKibbin in particular providing valuable assistance on the survey work.

In the course of this Review we consulted as widely as we could with managers, doctors, nurses, allied health professionals and, not least, patients groups, in our attempt to get behind the often rather dry descriptive statistics. A full list of those we talked to is included in Annex B.

Finally, I would like to acknowledge the hard work and commitment of Paul Montgomery (assigned full time to the Review from the Department of Finance and Personnel) and for his tremendous support in carrying through the Review to its conclusion.

2: Funding: Now and for the future

2.1 Introduction

Levels of funding, both now and in the future, are of critical importance and serve to set the overall boundaries or constraints of what is possible in terms of the services and care that can be delivered. This first section therefore examines historic and current funding levels in Northern Ireland, tracks current spending from various perspectives and importantly, adapts the approach and results employed by the first Wanless Review of future funding in the UK to suggest possible spending paths for health and social care services in Northern Ireland.

Section Conclusions

This section of the report has examined the main factors expected to impact on the level of resources required in the Northern Ireland health & social care sector in the coming years. Although there are some variations, these factors broadly reflect international trends. The demand for health care is expected to increase with the expectations of patients and the general public for a high quality, responsive, patient centred service. In terms of supply, technological developments will raise costs.

To quantify future resource requirements, Northern Ireland’s need adjusted share of the UK expenditure projections from the Wanless Review was estimated. A range of need factors were considered from the HM Treasury position of no adjustment for need to an optimistic needs adjustment suggested by DHSSPS. Whilst the current HM Treasury approach using the Barnett Formula is sub optimal - because the differing needs of the population in Northern Ireland are not recognised - the changes made to the needs assessment (NAS) model as part of the 2002 Needs and Effectiveness Evaluation could not be endorsed by the Review at this time as the supporting evidence required further development. Given this, the judgement of this Review (to be confirmed or denied in the light of any subsequent results arising from a UK-wide allocation model) is that a reasonable need differential between England and Northern Ireland should be around 7%.

This implies that additional real resources of between £3.3bn and £4.4bn will be required in the coming years to deliver a high quality service. The delivery of such a service is dependent not only additional resources but also how services are delivered. The level of public engagement and health seeking behaviour will also determine whether the resources required will be at the lower end of the range. In terms of immediate Northern Ireland Budget priorities, whilst the preferred need indicator would imply that the health & social care sector in Northern Ireland is currently over-provided relative to England, this does not mean that the health and social care services should receive anything less than its Barnet consequential. However, and as this review explores later, there is a concomitant commitment on the part of the health and social care services to explore ways in which current resources are used more effectively and efficiently to maximise the attainment of key goals for the benefit of patients, clients and users.

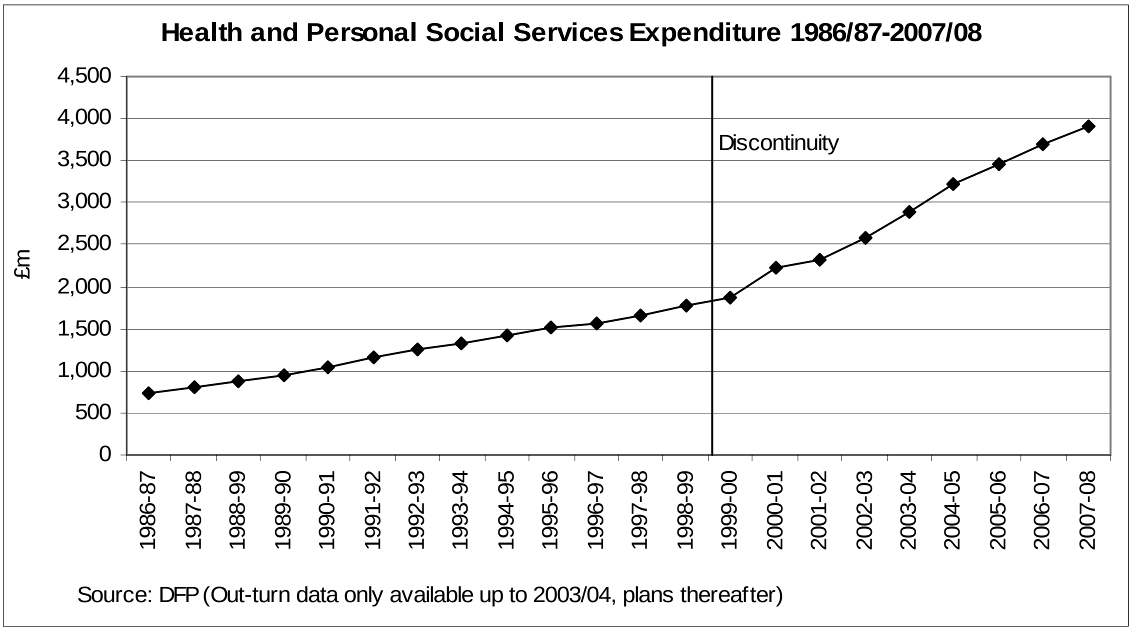
2.2 Historic trends in funding

To set some context for possible future spending on health and social care in Northern Ireland here we describe current and historic funding levels, making comparisons where possible with other regions and countries, outlining the global budget setting process for Northern Ireland, and analysing how recent increases in funding have been spent.

2.2.1 Funding levels

Figure 2.1 shows that the funding available for health and personal social services (HPSS) has increased significantly over the past twenty years. In addition, whilst comparison are made more complicated by changes in accounting practices there does appear to have been an increase in the growth rate of HPSS spend subsequent to 1999/00 which is expected to continue under current Government spending plans.

Figure 2.1: Health and Personal Social Services expenditure is expected to have increased by 8.4% a year on average over the twenty years since 1986-87[2]



Source: DFP (Out-turn data only available up to 2003/04, plans thereafter)

Comparing levels of health and social services expenditure between countries or regions is not an exact science; definitions of care vary and the way spending is accounted for can also differ. Further, it is unwise to assume that higher spending necessarily means better health outcomes or greater activity. And similarly, it should not be assumed that all spending differences are unjustified; differences in the need for health and social care and the efficiency with which different systems convert financial inputs into health care outputs and health outcomes often provide legitimate reasons for differences in levels of spending .

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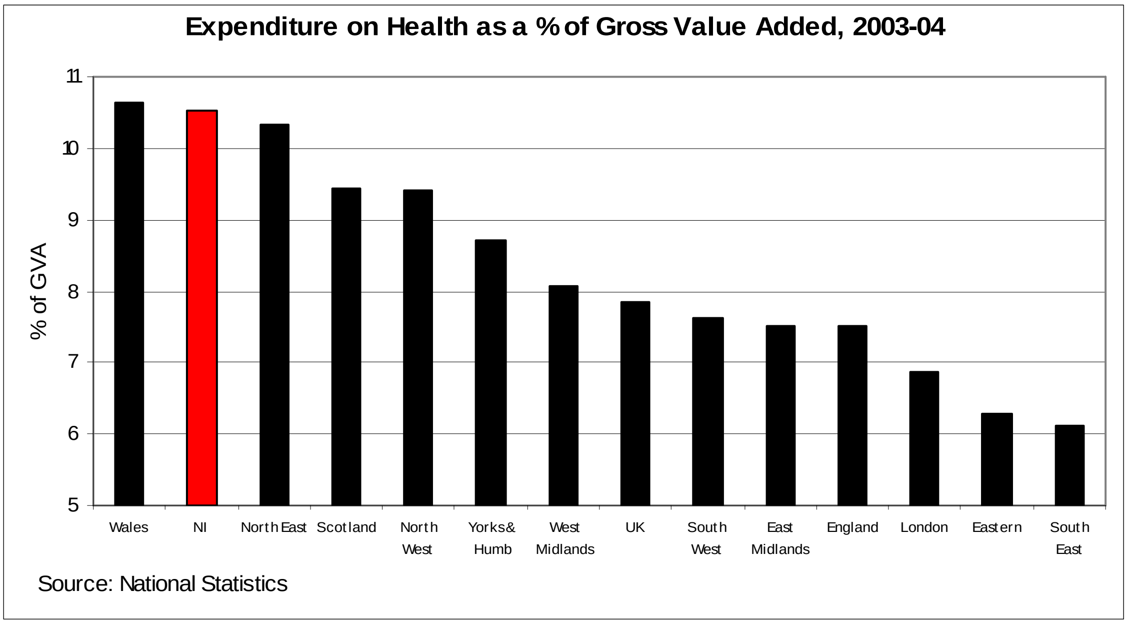
[2] Changes in accounting practices particularly in 2000/01 with the move from cash to accruals means that comparisons in spending over time need to be treated with care whilst the transfer of Preserved Rights and Residential Care Allowances from DSD resulted in a significant one-off uplift. Therefore the Figure is intended to be illustrative only.

Bearing these caveats in mind, there are a number of ways in which relative levels of expenditure on health and social care can be considered. The 2001 Interim Wanless Report presented health expenditure in the context of overall economic activity. On this basis, figure 2.2 shows health spend (excluding social care) as a proportion of Gross Value Added (GVA)[3] for the UK regions.

Figure 2.2: 11% of the value of all economic activity in Northern Ireland is devoted to health care (health excluding social care spending a percentage of GVA for UK regions, 2003-04)



Source: National Statistics

Although on this basis Northern Ireland has the second highest level of health spend, this is more a reflection of the region's relatively low level of GVA per head than its health spend[4].

A better measure of the relative level of health spend is on a per head basis - as shown in figure 2.3. Figures for 2004/5 show that Northern Ireland had the fourth highest level of spend per head on health of all the UK regions, and spending was 7.3% higher than the UK average. The general pattern revealed in the figure is to a large extent to be expected; per capita funding allocations in England, for example, are specifically designed to be unequal, being driven by the need health care as part of a general policy to improve equity of access to the NHS.

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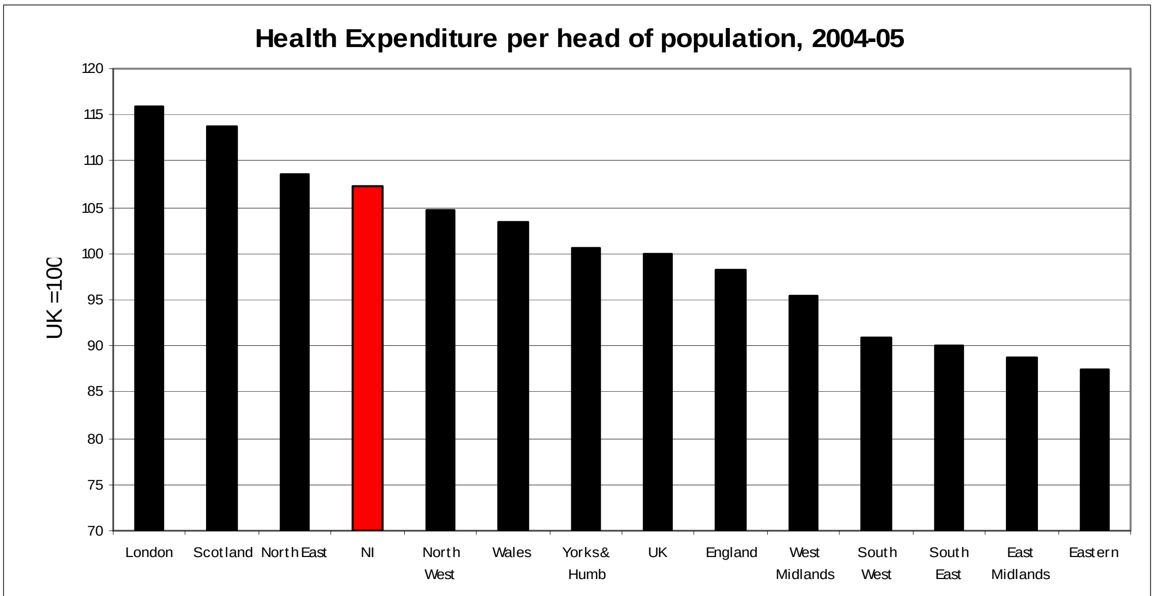
[3] Gross Value Added is the current preferred measure of economic activity for UK regions replacing Gross Domestic Product

[4] Around three-quarters of the difference in health spend as a % of GVA between NI and the UK as a whole can be accounted for by NI's lower level of GVA per head.

Figure 2.3: Northern Ireland spends 7% more per head of population on health care services (excluding social services) than the UK average(2004-05 (UK =100))



Source: National Statistics

It is important to note, however, that there is no resource allocation mechanism across the whole of the UK; while differences in need may explain some or indeed all of the differences in per capita spend between Northern Ireland and the rest of the UK, this should not be assumed to be the case.

During the 1990's, per capita health and social care spending in Northern Ireland was consistently higher than in England (although lower than Scotland) in spite of the operation of the Barnett Formula[5](after the former Chief Secretary to the Treasury, Joel Barnett, who, in the 1970s, proposed it as a short term solution to Cabinet disputes over spending). However, in more recent years, the spend per head gap with England has narrowed (see figure 2.4). In the context of this trend continuing, it is important to have clarity as to the extent to which the need for health expenditure in Northern Ireland is higher than in England. This issue is addressed in Section 2.3.4

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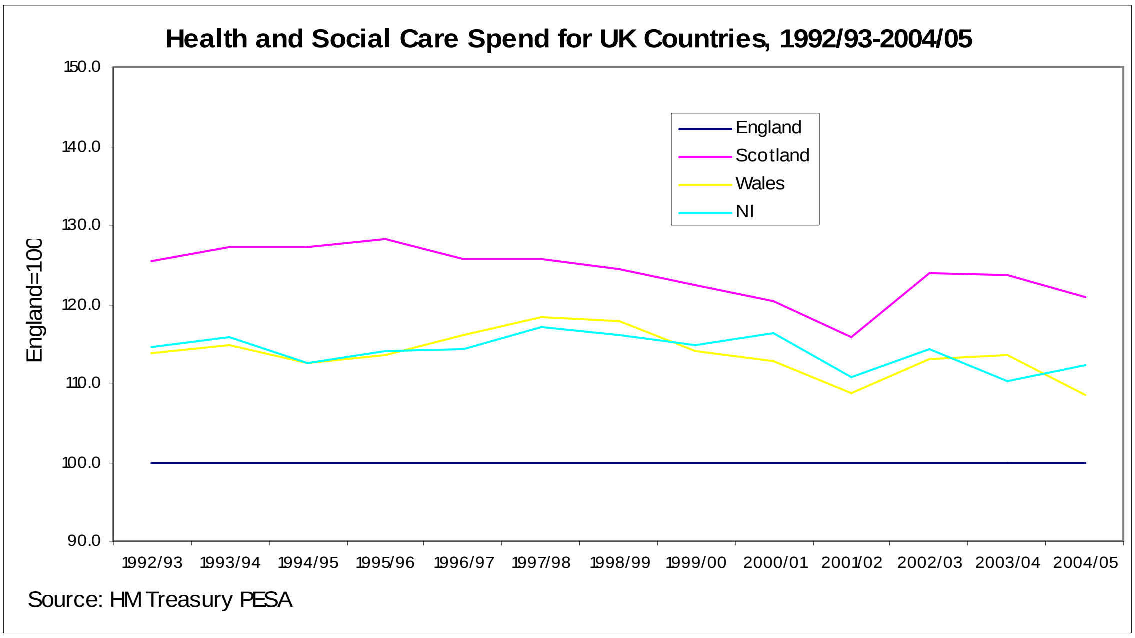
[5] The Barnett formula (discussed below) operates by allocating Scotland, Wales and NI its population share of growth in expenditure in England and as such is expected to lead to asymptotic convergence in spend per head levels between the UK countries. There are other minor adjustments to take account of the fact that some services are delivered on a UK wide basis and it would not be appropriate for the devolved administrations to receive a share whilst there is a VAT abatement factor applied specifically to Northern Ireland

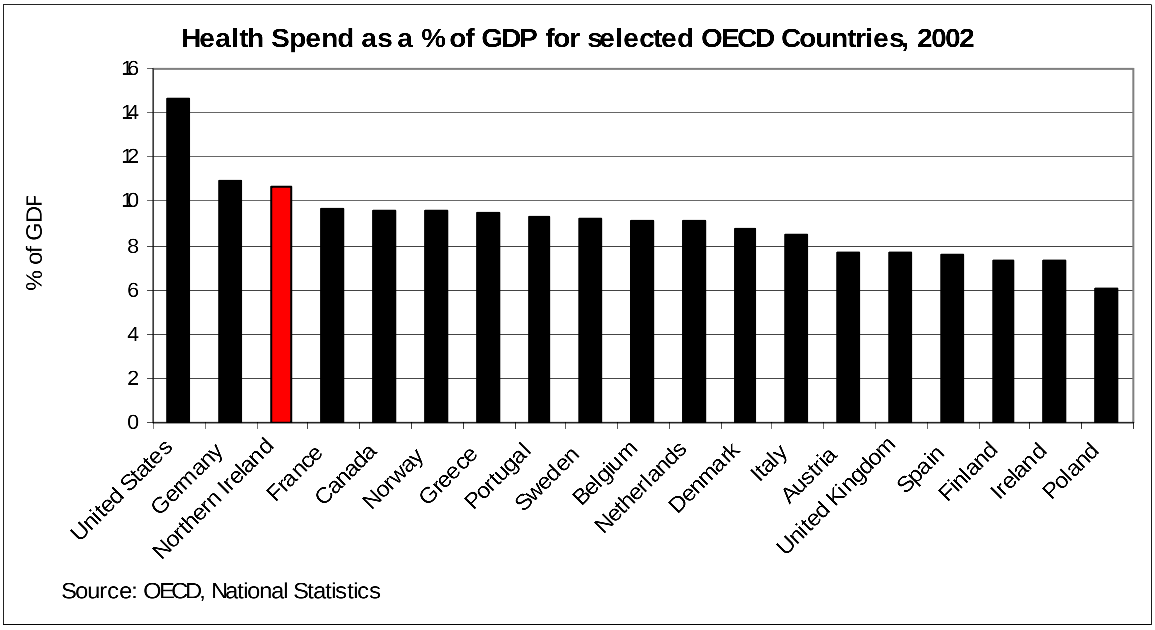
Figure 2.4: There has been some marginal convergence in the level of Health and Social Care spend per head for UK countries since 1992-93



Source: HM Treasury PESA

Internationally, figure 2.5 shows that expenditure on health care in Northern Ireland as a proportion of GDP is higher than all OECD countries with the exception of Germany and the United States.

Figure 2.5: Northern Ireland has a relatively high level of Health (excluding social care) Spend as a percentage of GDP compared to selected OECD countries ($PPP basis), 2002

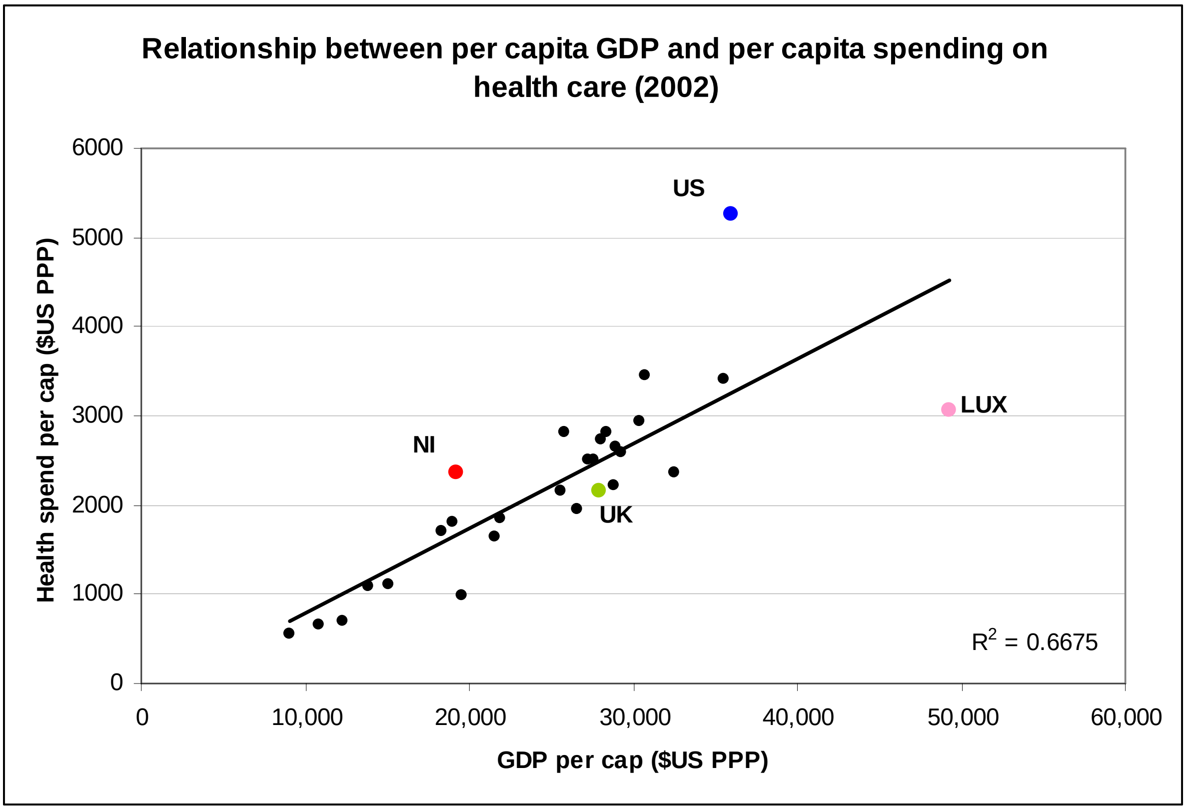


Source: OECD, National Statistics

However, as with spend as a proportion of GVA, the relatively high spend as a proportion of GDP is in part explained by the fact that Northern Ireland's per capita GDP is comparatively low. As figure 2.6 shows, Northern Ireland appears to spend more than might be expected given its per capita GDP. In fact, from this point of view, Northern Ireland appears to be spending nearly 30% more than expected. For comparison, the UK as a whole is spending around 16% less than expected and the US 38% more.

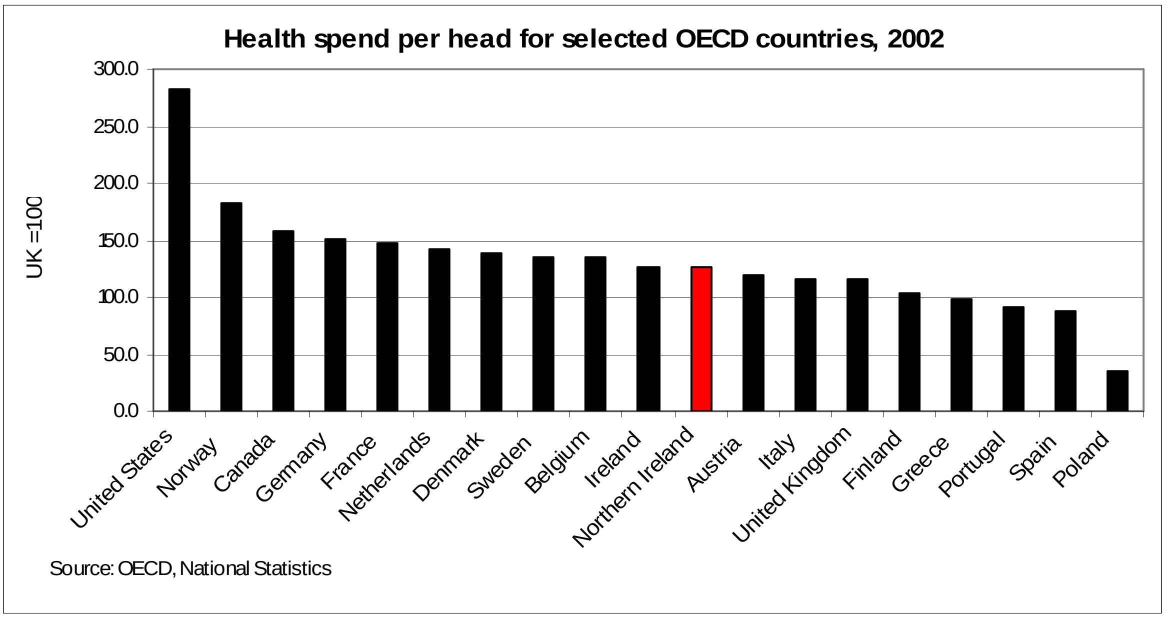
But this apparent position of overspending relative to its GDP is, as already noted, partly explained by Northern Ireland's relatively low level of GDP. In looking forward to what might be a reasonable and, in particular, an *affordable* level of spending we note in section 2.3.4 that international comparisons based on GDP are, for various reasons, problematic when considering Northern Ireland's position.

Figure 2.6: Northern Ireland appears to spend more on health (excluding social care) care than might be expected given its per capita GDP



The difficulty of using health spend as a share of national or regional wealth is highlighted when comparing Northern Ireland's spending on a per capita basis. As figure 2.7 shows, from this perspective, Northern Ireland slips down the international spending league table.

Figure 2.7: Health (excluding social care) spend per head for selected OECD countries ($PPP basis), 2002



Source: OECD, National Statistics

Overall, while Northern Ireland currently has a higher level of health expenditure than most UK regions, in an international context, spending - in particular, per capita spending - is not particularly high

2.2.2 Setting global and local health and social care budgets

Since 1998, the Spending Review - announced bi-annually for public spending commitments three years forward[6] - has set the starting position for determining health and social care spend in Northern Ireland. With regard to the devolved territories, and health and social care spending in Northern Ireland in particular, the Spending Review produced by HM Treasury sets out spending in England, which forms the basis for a specific health and social care allocation through the operation of the Barnett formula.

The ‘formula’ is not sophisticated; it does not reflect differential health and social care needs or variations in the costs of providing services. In essence it uses the shares of total population to set the *change* in spending (not the total amounts) on certain public services in Scotland, Wales and Northern Ireland to ensure that decisions on spending (primarily in England) are reflected in other parts of the UK.

Currently, for example, a 10% increase in NHS spending in England would - via the formula - translate into an 8.9% increase in the equivalent allocation (from general taxation across the UK) for Northern Ireland[7]. Over the coming years, if the use of the Barnett Formula were to continue, this would suggest that spending increases will converge.

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[6] The exception to this was the 5 year commitment to health spending set out by the Chancellor in the Spring of 2002 which was applied to England but not the rest of the UK. In practice DHSSPS have only been able to plan on a one-year basis.

[7] Based on the 12.2% higher level of HPSS spend in Northern Ireland than England in 2001-02

In practice, however, the actual health and social care services spend in Northern Ireland has been supplemented. Firstly, from decisions concerning the annual Northern Ireland Budget, which determines the shares of spending across all public services in Northern Ireland. And secondly, from in-year allocations (and occasionally subtractions (reduced requirements)) from (to) other budgets as a result of in-year monitoring of the state of budgets across the public sector. These latter sources of funding can be substantial, and have, between 2000/1 and 2003/4, accounted for a third of the total increase in Northern Ireland's spending on health and social care services (see Box 2.1)[8]

> **Recommendation 1: In the light of suggested future funding (see Recommendation 3), in-year monitoring additions to health and social care budgets should cease other than in exceptional circumstances and solely on a one-off basis.**

2.2.3 Tracking spending

Tracking funding from these different sources can be difficult, but it is vital not only to understand in accounting or financial probity terms where and on what budgets were spent, but also to provide policy makers and the public with information which connects up the tax-spend-outputs cycle and to monitor spending associated with policy commitments: in other words, how are the financial inputs connected to the health and social care outputs?

This section of the Review, therefore, attempts a broad audit of recent years' health and social care spending.

Total health and social care spending can be analysed from a number of points of view. Below we examine spending on the basis of:

- Global spending trends in HSPSS capital and revenue
- Cost pressures (for example, pay inflation)
- Trends by sector (such as hospital and community health services)
- Organisation
- Programme of Care (POC) - such as acute and mental health
- Hospital, social and community care
- Labour inputs - health and social care staff expenditure

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[8] The DFP view is that In-year monitoring is to cater for unforeseen pressures – not an opportunity to bid for resources not obtained in the previous budget, although this is often the case.

Box 2.1: Sources of funding for health and social care services

The Northern Ireland Priorities and Budget process is an annual budget process which allocates the resources to central government departments and public bodies in Northern Ireland in line with local priorities and needs. Departments submit bids for additional resources detailing the specific purposes for which they are intended which are then analysed and prioritised by DFP. Recommendations on the level of funding, and the purposes for which it is intended, are submitted to the Finance Minister for consideration and discussion with ministerial colleagues. Following public consultation and further ministerial discussions and agreement, the Secretary of State approves the final Priorities and Budget outcome.

Departmental budgets are agreed by the Secretary of State at Unit of Service level (see Figure 2.11) and a detailed control annex listing specific allocations at Unit of Business level is notified to each department (neither of these are aligned with Programmes of Care). While departments have always been expected to adhere to the allocation detail included within the control annexes or to discuss any proposed reprioritisations with DFP, there is some concern that in some material cases, this was not happening. As a result, this year, for the first time, Settlement Letters have been issued to departments (with the associated control annexes), emphasising that departments must consult with DFP before using resources specified for particular purposes (as noted in the control annexes) for any other purpose. As regards HPSS spend, this is intended to provide an assurance that the wishes of Ministers are being respected.

Allocations to Boards represent the bulk of the HPSS budget and are distributed according to a capitation formula taking account of issues such as age, sex, poverty, sparsity of population etc. While DHSSPS ring-fence certain allocations prior to applying the capitation formula, Boards, in discussion with Trusts, determine how each share is allocated to meet the needs of local populations. The other significant element of the HPSS budget relates to the funding of Family Health Services which, on the whole, operates on the same basis as in England. The remainder is accounted for by an array of centrally managed programmes for example medical/dental education and training.

While the DHSSPS allocation is agreed by the Secretary of State at Unit of Service (and implicitly at Unit of Business) level, other than where certain allocations are ring-fenced, most of the allocations to Boards are made on a bulk capitation basis. Therefore, although the Department establishes PSA targets that are subsequently linked to the HPSS PfA, Boards' business plans, and Trusts' Delivery Plans, it has proved very difficult for DFP to track whether specific budget allocations have been used for the purposes intended.

Global spending trends

Expenditure data taken from the final out-turn Budget position held by the Department of Finance and Personnel[9] shows that between 2000-01[10] and 2004-05, health and personal social services expenditure increased by £981m or 9.5% per annum on average (figure 2.8). Over the next three years the pace of growth is planned to slacken to around 6.7% per annum, although this still represents an additional £700m of resources between 2004/5 and 2007/8 at a time when total planned allocations will increase by only 5.1% per annum.

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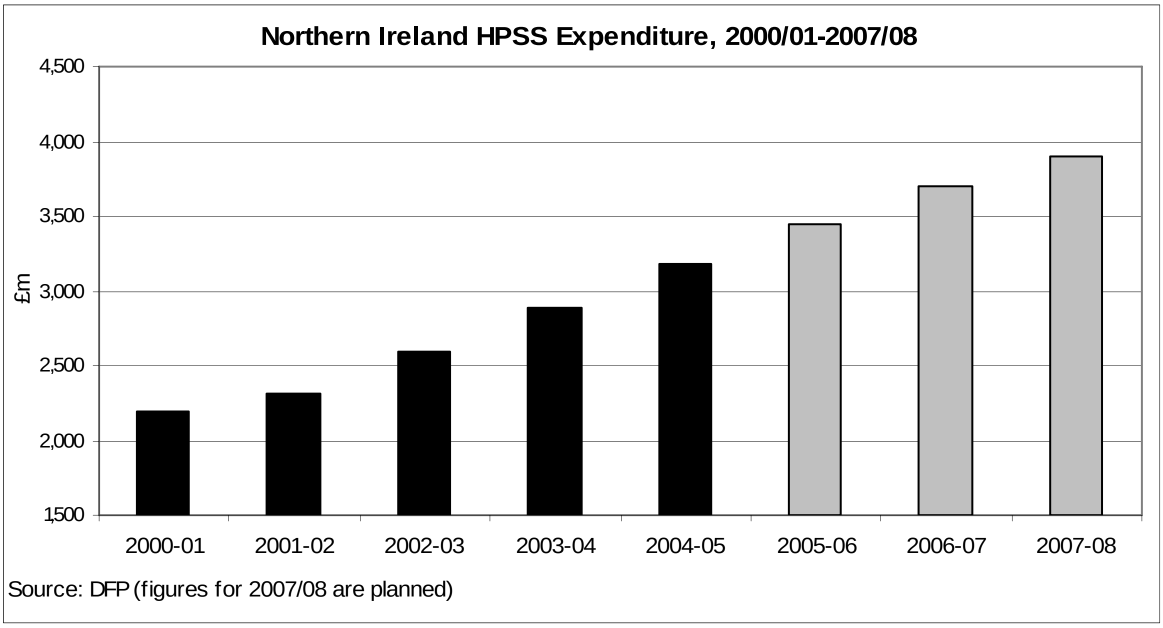
[9] All data is final out-turn except for 2004-2005 where only February monitoring is available, consequently the expenditure for the current year may change between final expenditure as currently planned and the outcome as reported after the financial year has ended. Any changes should however be minimal and the data reported here should be broadly accurate.

[10] This data has been prepared from the final out-turn Budget position and exclude non-budget items and PSS accruals.

Figure 2.8: Northern Ireland HPSS spending has increased by nearly 10% per year in cash terms since 2000/1, but planned increases to 2007/8 will be around 7% per annum.



Source: DFP (figures for 2007/08 are planned)

Cost pressures

Every year, a significant proportion of the cash allocated to HPSS is swallowed up by higher costs arising from increases in prices and pay. Here we examine these and other cost pressures over recent years and expectations for years up to 2007/8.

Figure 2.9 shows that almost half of the health and personal social services Budget allocation in Northern Ireland is, as expected for a labour intensive industry, spent on pay. The next largest share is on medical supplies, catering & cleaning which also includes hospital drugs, residential home costs, domiciliary care and foster care allowances.

Between 2001/02 and 2003/04 approximately a quarter of the additional funds allocated to HPSS were made available for additional services with around three quarters required for pay and price uplifts[11]. However, allocations from the Northern Ireland Budgets for 2002 onwards, imply that only 5.8% of the growth in spending between 2004/05 and 2007/08 is likely to go towards service developments

Most of the cost pressures relate to inflationary uplifts for pay and prices - as shown in figure 2.10. New contracts and staff reviews are also expected to increase HPSS expenditure between 2003/04 and 2007/08 by around £134m with £62m attributable to the implementation of Agenda for Change, £41.4m for the new GMS contract and £14.5m for the new consultants' contract[12].

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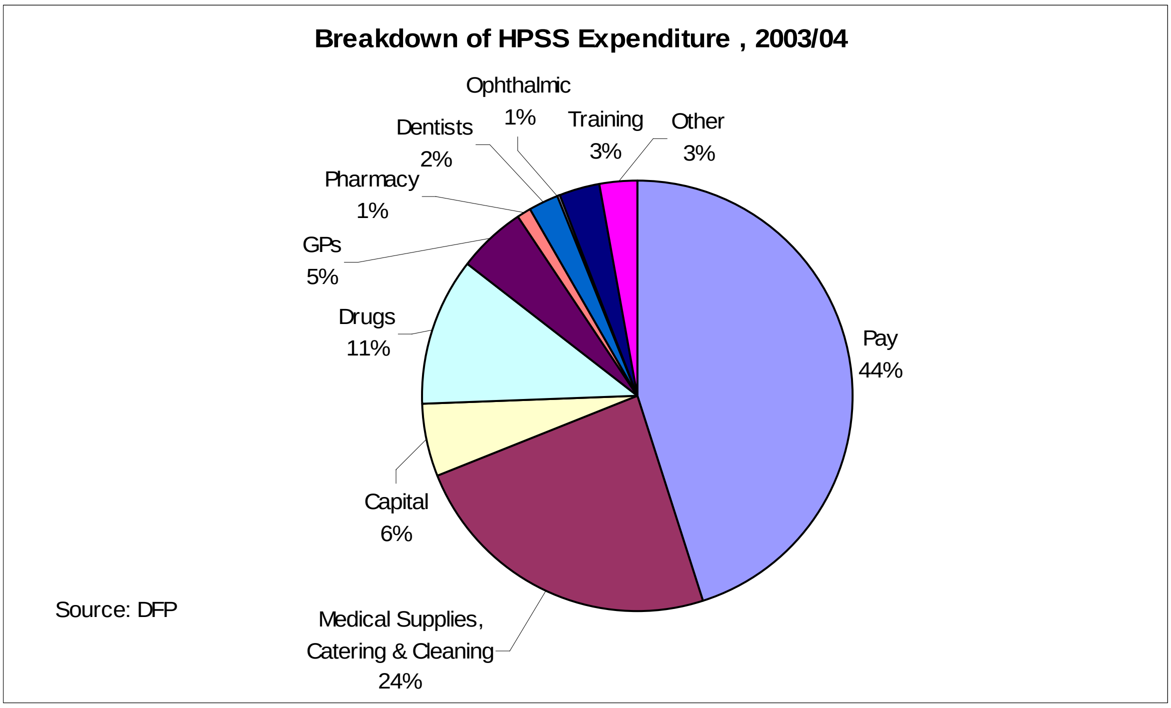
[11] There is some disagreement between DHSSPS and DFP on this matter with DHSSPS arguing that only 14% of funds were available for service developments.

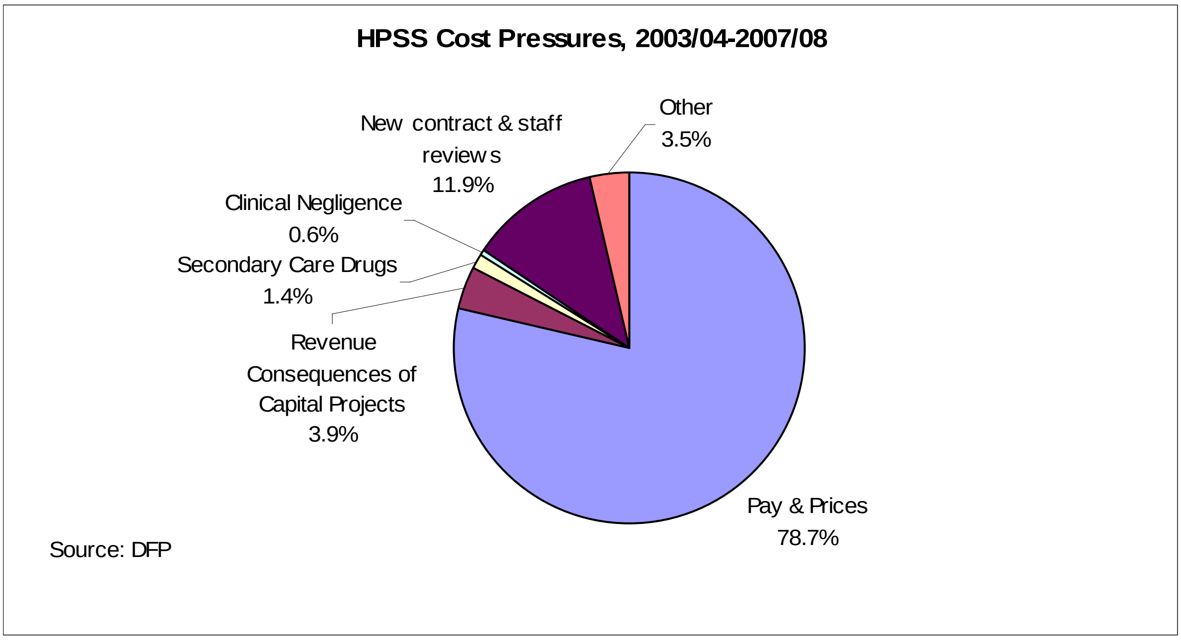
[12] Collectively pay reforms are expected to increase HPSS staff costs by 7.2% (i.e. £92.5m/£1,283m.) in addition to the general pay uplift for performance and cost of living

Figure 2.9 Pay is the largest single item of the Health and Personal Social Services Budget allocation, 2003/04



Source: DFP

Figure 2.10: The most significant HPSS Cost Pressure over the period 2003/04-2007/08 will be pay & prices inflation[13].



Source: DFP

Trends by sector

The HPSS budget is agreed by Ministers in terms of the ten Units of Service, although figure 2.11 shows that the bulk of HPSS expenditure is concentrated in the Hospital and Community Health Services (HCHS), Personal Social Services (PSS), and Family Health Services (FHS). However, when the budget allocations are formally notified to DHSSPS, a more detailed description of what they are intended

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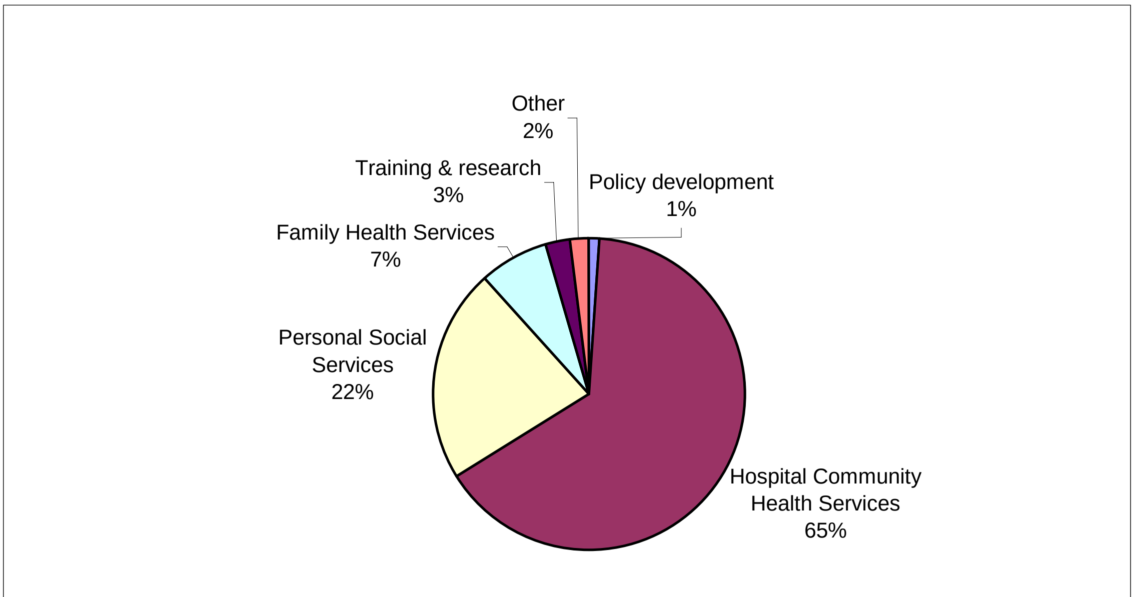
[13] Pay and Prices cost pressure include an element of drugs.

to be spent on is included in what is known as the budget control annex. In an effort to track allocations agreed by Ministers to actual spend, a settlement letter has been issued to each department for the first time this year, emphasising that departments must discuss with DFP before re-allocating any resources for purposes other than what was agreed as part of the budget process.

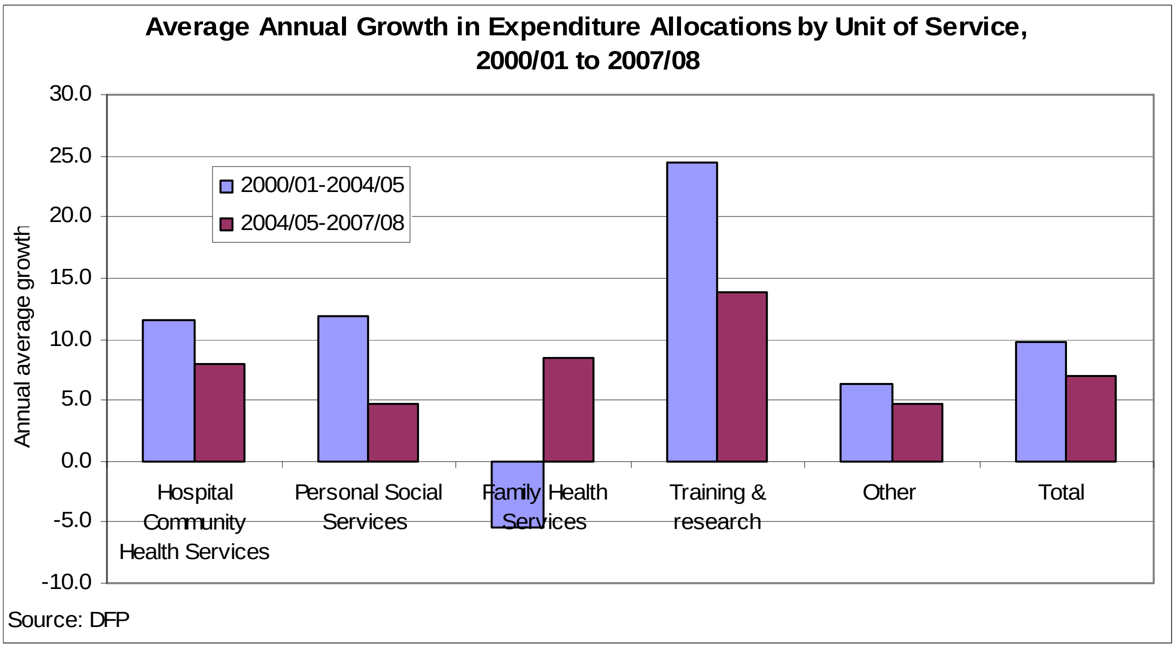
Figure 2.11 The majority of the HPSS Expenditure allocation by Unit of Service is expected to be spent on Hospital and Community Health Services, 2004/05



Source: DFP

HCHS have absorbed an increasing share of total resources (a trend that is expected to continue) as shown in Figure 2.12. In 2007/08, HCHS is expected to account for nearly 70% of all spending - an increase of 6 percentage points since 2000/01. The higher growth in HCHS spend between 2000/01 and 2004/05 is in part due to the re-allocation of pharmaceutical spending from the FHS. The higher growth in HCHS spend appears to be inconsistent with general move to shift treatment from a hospital to a community/social setting where appropriate.

Figure 2.12: The annual average growth in spend for Hospital Community Health Services has been greater than that for Personal Social Services over the period 2000/01 to 2007/08[14].

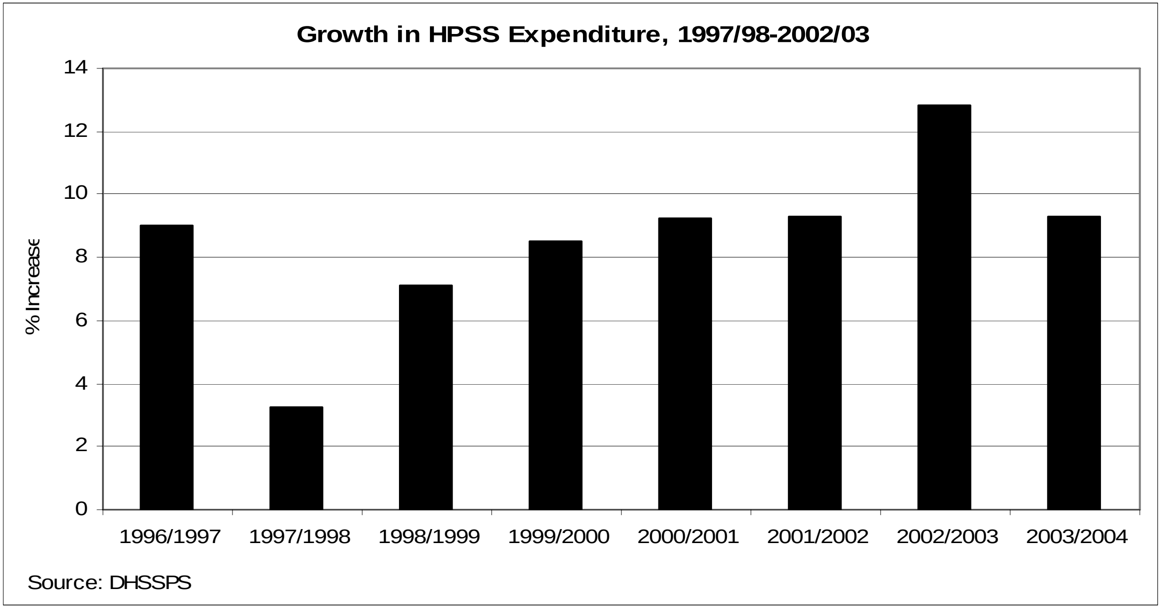


Source: DFP

Trusts

Around three quarters of the total HPSS spend is accounted for by trust spending with remainder carried out by GP’s or centrally by DHSSPS. Expenditure by Trusts has increased by almost £950m - 8.5% per year - between 1995-96 and 2003/04 to stand at £2.0bn. Figure 2.13 shows that there was a steady increase in the growth rate of HPSS expenditure since up until 2002/03, whilst the slower level of growth in 2003/04 is expected to continue over the current budget period.

Figure 2.13: Growth in HPSS expenditure has increased year on year between 1997/98 and 2002/03



Source: DHSSPS

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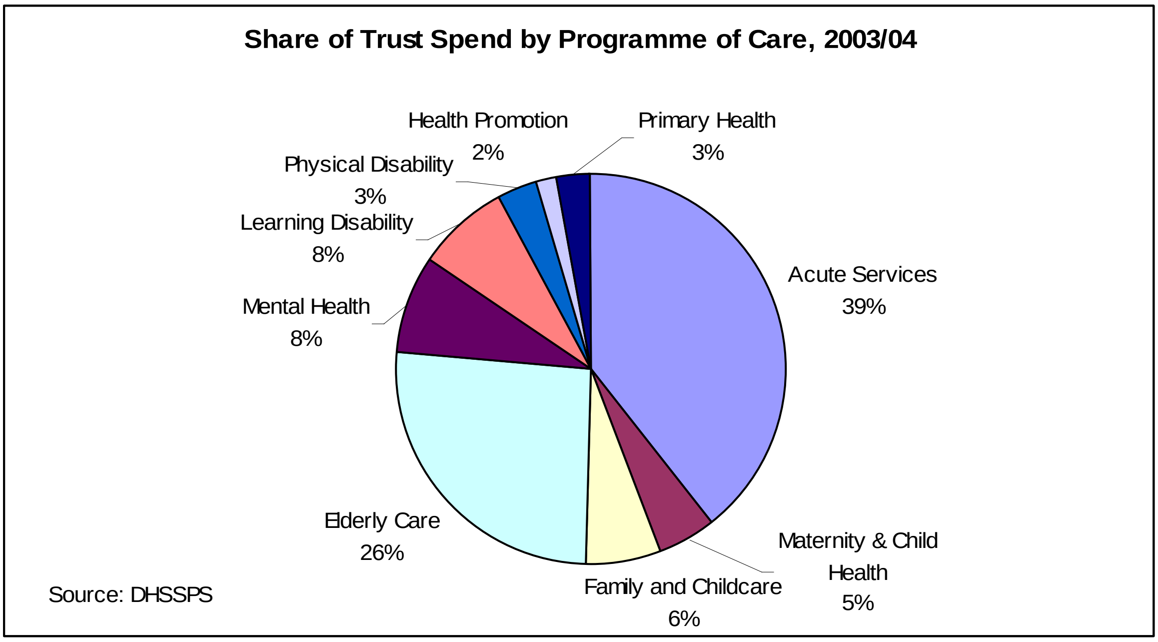
[14] However there appears to be a significant changes over time in the unit of service that particular items of expenditure are classified under. Whilst, DFP have provided as consistent a series as possible the chart should sill be treated as indicative only

Three trusts - the Royal Group, Ulster and City, located in the Greater Belfast area - collectively account for over a quarter of total HPSS spending in 2003/04. These trusts have also experienced growth in expenditure significantly higher than the average for Northern Ireland Trusts. For example, expenditure at the Royal Group of Hospitals increased by 10.7% per annum compared to the Northern Ireland average of 8.5% over the period1995/96-2003/04

Programmes of care

DHSSPS tracking of HPSS trust expenditure is currently available from 1995/96 to 2003/04. This allows trends in expenditure by Programme of Care[15] (POC). From this point of view, one of the consistent themes from the consultation process was the perception that funds were being diverted from other POC's towards the acute sector. Whilst DHSSPS bids for expenditure to DFP relate in many cases to specific POC's the block allocation of funding through the capitation formula would suggest that it is at the discretion of Boards and Trusts as to the distribution of expenditure between POC's. However, DHSSPS have indicated that in recent years there has been greater direction given by the Department to ensure that funds are used for the purpose intended. Although acute services dominate the HPSS sector - accounting for two-fifths of total spend (figure 2.14), at least over the period 1995/96-2003/04, growth in spend for the acute services was only slightly higher than the overall average (figure 2.15). However, its share of the total has increased slightly in recent years, and anecdotal evidence would suggest that this has continued in 2004 and 2005.

Figure 2.14: Acute services account for nearly two fifths of total spend….



Source: DHSSPS

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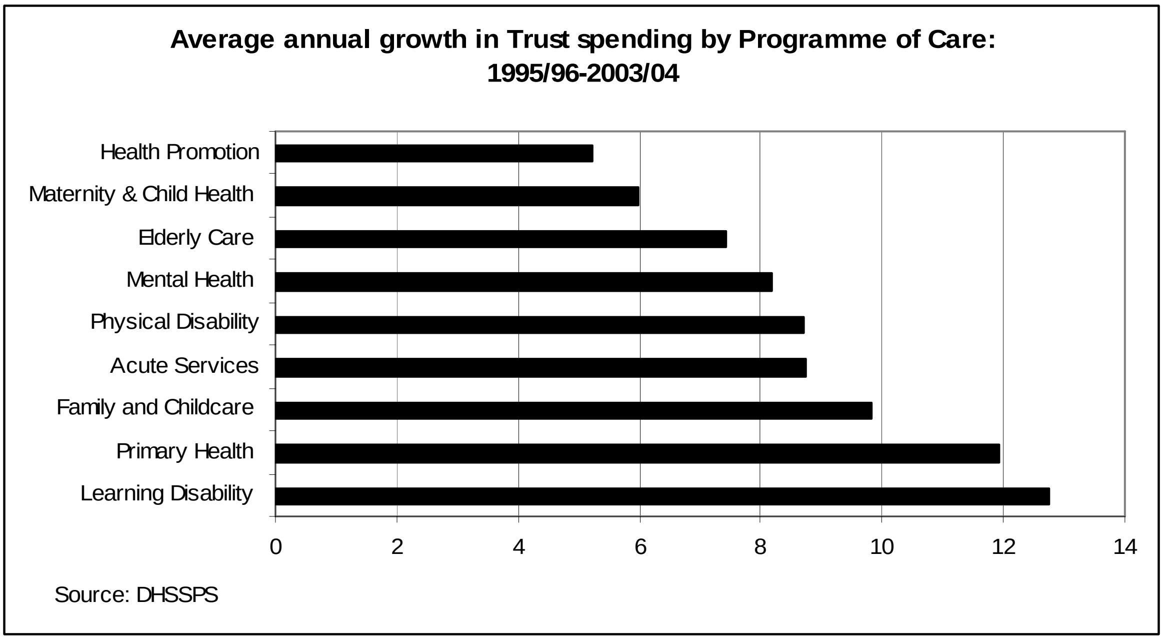
[15] Programmes of Care are divisions of healthcare, into which activity and finance data are assigned, so as to provide a common management framework. They are used to plan and monitor the health service, by allowing performance to be measured, targets set and services managed on a comparative basis. In total, there are nine Programmes of Care.

Figure 2.15….but acute services spending has grown more slowly than a number of other services.



Whilst the Learning Disability POC had the highest level of growth in expenditure over the period 1995/96-2003/04, its relatively small scale meant that it only accounted for a tenth of the overall growth. Given the demographic trends in Northern Ireland with a falling birth rate and ageing population it is to be expected that spend on Maternity and Childcare should have grown at a slower rate than the Northern Ireland average. However it is surprising that growth in spend on elderly care should be lower than the overall average whilst the low level of growth in expenditure on health promotion suggests a lack of investment for the future[16]. The dominance of the three largest Belfast Acute Trusts (Royal, City & Ulster) can be seen particularly with respect to the Acute POC where they account for 47% of total Northern Ireland spend in 2003/04 and 53% of spend growth since 1995/96.

In 2003/04 hospitals accounted for 54% of trust spend, reflecting the importance of the acute programme of care, followed by personal social services (33%) and community services (12%). Over the period 1999/00-2003/04 growth in hospital expenditure was less than both PSS and community services. The greatest contribution to the increase in trust spend over this period was from acute services (41% of total growth). More detailed analysis of Trusts Expenditure is set out in Annex C

Health and social care staff

Current allocations (post initial implementation of Agenda for Change, Consultants' Contract and GMS Contract) show the proportion of all HPSS expenditure accounted for by direct pay and pension cost remaining stable at just over one half for the next number of years. In the entire period 2000-01 to 2007-08 just under 60% of the increase in HPSS expenditure will have been absorbed in pay costs.

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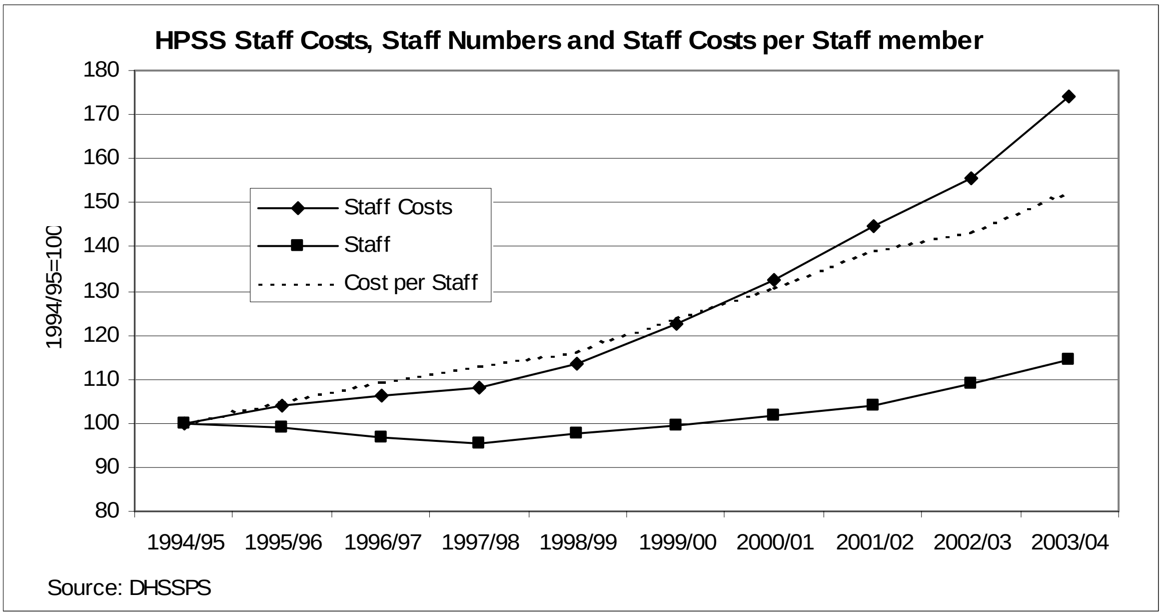
[16] DHSSPS have suggested that the slower growth in the funding for elderly services may be due to previous over-funding of this POC. This raises the question as to whether DHSSPS should be more aware as to the appropriate level of funding across POCs.

Figure 2.16 shows that spending on staff costs by HPSS trusts has increased by 6.4% per annum from 1994/95 to 2003/4. Whilst wages and salaries have risen by 4.8% over this period, the number of staff has only increased in recent years, and at a slower rate (1.5% pa)[17].

Figure 2.16: Staff Costs have increased at a faster rate than the number of staff in the HPSS between 1994/95 and 2003/04



Source: DHSSPS

Over the period 1997/98- 2003/04, approximately 59% of the increase in HPSS expenditure was due to staff costs. This means that approximately 37% of the increase in HPSS expenditure over this period was due to increases in staff costs per head, with the remaining 23% due to increase in staff numbers[18]. However, there is significant variation in the rate of increase in staff costs per head between staff groups. Medical staff enjoyed growth of 7.6% per year in wages and salaries compared to the HPSS average of 5.1%, and 4.9% for trained nurses. The increase in wages and salaries within HPSS trusts was higher than those in the general economy (on a mean or median basis) as measured by the Annual Survey of Hours and Earnings.

Linkage between allocations and actual expenditure

As referred to above, a key concern regarding the health & social care sector in Northern Ireland has been the apparent lack of linkage between specific funding allocations to the department and subsequent service delivery. This has lead to the description of the health & social care sector as a financial black-hole where despite apparent significant additional funds there is little progress in resolving problem areas such as waiting lists. This phenomenon relates not only to Northern Ireland

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[17] Between 1994/95 and 2003/04 the number of whole time equivalent staff in the HPSS has increased by just over 6,100 or 14.6%. The administration & clerical staff grouping experienced the largest increase in numbers (+2,400) whilst medical staff and trained nurses each increased by between 700-800.

[18] Between 1997/97 Total HPSS spend increased by £819m whilst staff costs increased by £487m with growth of 5.1%pa in staff costs per head and 3.0%pa in staff numbers.

but to the rest of the UK where the additional funds allocated do not appear to have resulted in a commensurate increase in activity. Whilst there are a number of reasons why the impact of additional funding has to date not been captured by headline indicators of performance there remains the concern that value for money has not been achieved.

In order to shed some light on this issue DHSSPS were asked to produce evidence linking as closely as possible their successful bids for expenditure with subsequent patterns of spend. Additional funds are allocated to the health & social care sector through a range of mechanisms including the outcome of Northern Ireland Budget Rounds, In –Year Monitoring, Northern Ireland Executive Programme Funds and European Funding. Whilst the largest share of additional funding comes from the Northern Ireland Budgets, the allocations from these sources are hardest to link to specific activities as they tend to fund general uplifts for pay and prices. It can be seen that additional funds are allocated for a broad range of services. For example, over the period 1999/00 to 2003/04 an additional £22.8m was allocated to dealing with Waiting Lists, £20.9m for Winter Pressures and £24.3m for Child Care services.

These additional funds were then linked to changes in spend for Hospital, Social and Community Services from Trust accounts data. Table 2.1 below shows that the increase in real Hospital spend for 2000/01 of £37m is equal to the associated budget bids.

In respect of hospitals, therefore, it does appear to be possible to track the funds through to actual expenditure. However, there are a number of caveats to this assertion, in particular that the correlation between bids and expenditure growth might have been achieved by simply allocating the large number of bids selectively to ensure the desired result.

Table 2.1: Reconciliation of Budget bids and real hospital expenditure growth 2000/01

	Budget Bids (£m)	Real Increase in Expenditure (£m)
Cancer Services	8.0	
Dependency Beds	2.4	
Fracture Services	1.0	
Medical Emergency	5.0	
Waiting List	1.3	
Winter Pressures	3.0	
Acute Services	5.0	
South Tyrone	5.5	
Causeway	0.5	
Clinical Waste	4.2	
Omagh	0.6	
MRI	0.5	
Hospital Total	37.0	36.4

In addition, the figures are insufficiently detailed to check whether, for example, the £8m allocated to Cancer Services was spent on those services rather than another aspect of hospital services. Indeed, even if there was an additional £8m spent on

Cancer Services this may have not have had the impact on actual outcomes for patients that would have been expected when the bid was agreed by Ministers.

In the case of community and social services, the transition was less transparent, mainly because funds tended to be allocated in the form of general funds to be shared across services and programmes of care. There were also a number of adjustments of significant scale such as the transfer of Preserved Rights which also distorted comparisons[19].

Further, as the actual expenditure data relates to trusts only there were a significant number of bids that were not allocated to a particular service such as equality and training.

Analysis of spend data has shown the difficulty of tracking expenditure throughout the system. Greater transparency would require more detail to be set out when putting forward bids in terms of the specific service/programme of care that the bid relates to and where possible what the resources will be used for in terms of staff, equipment or care packages. Whilst it is reasonable that there should be appropriate control on the use of public funds the cost of excessive micro-management particularly in the context of greater devolved decision making to frontline staff also needs to be recognised. There is however scope to tighten up the target setting process particularly with respect to Public Service Agreements to ensure that the objectives which resources are allocated to, lead to measurable improvements in service.

> **Recommendation 2: Over and above the need to track spending for reasons of financial probity, the main performance policy monitoring focus should be on tracking outcomes, not spending per se. A programme budgeting approach - as currently being developed in England for 23 disease/service groups - in addition to traditional accounting would be of help with this.**

Conclusion

The HPSS sector in Northern Ireland appears on initial analysis to be well funded in a UK context and reasonably funded in an international context. However, this is based only on analysis of the level of spend per capita and takes no account of the potential need for higher spend in Northern Ireland, which will be discussed at a later stage.

The decision making process when allocating health and social services expenditure appears to be convoluted. Although the expenditure bids agreed by Ministers include detail as to how the resources are to be used the subsequent block funding of Boards to distribute money to Trusts would suggest that decisions are also made at this stage based on local needs as to how funds should be allocated. Whilst there is direction from and monitoring by the DHSSPS as to the use of resources there remains considerable scope for confusion with same decisions being made at various stages in the process. There is a tension between the need for clear direction and control from the centre to ensure that the wishes of Ministers are

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[19] Whilst additional funds were transferred with Preserved Rights, the view of DHSSPS is that the cost of funding residential nursing care was in excess of these funds

implemented and the need for flexibility to ensure that local needs can be satisfied in the context of changing circumstances.

In terms of how the additional funds allocated to the HPSS sector have been used, the evidence available to date would suggest that the distribution of funds reflects past spending patterns, with the largest share going to the Acute Sector although not on a significantly disproportionate basis.

Since 1997/98 although the share of total expenditure accounted for by staff costs has declined, this item still accounts for a significant share of the overall growth in spend as has been the case in England. In particular, growth in wages and salaries accounts for over two-fifths of the increase in HPSS expenditure. Staff numbers have also risen with the largest increase in terms of administrative & clerical staff. Whilst it can be argued that wages are an important element in the recruitment, retention and motivation of staff and support to frontline services is also important, the relatively moderate increase in hospital activity over this period relative to England is of concern.

A key concern that was raised as part of the consultation process was that the funds allocated to the health & social care sector were not being used for the purpose intended. It has been shown, however, that there does appear to be a reasonable link between budgetary allocations and subsequent expenditure for Hospitals. For social and community services on the other hand, the link is much less clear although this is in part due to the way in which the funds are allocated.

2.3 Funding in the future

An important part of the terms of reference for this Review was to examine the:

'Technological, demographic, medical and other trends over the next two decades that may have implications for the future resource needs of the HPSS sector in Northern Ireland consistent, where possible, with the approach adopted in the Wanless Review.'

In approaching this aspect of the Review two points need to be kept in mind. First, there is no objectively correct answer to the question of how much should be spent on health and social care.

For health and social care in Northern Ireland, as for other publicly funded care systems, total spending levels are a matter of fiscal choice. This does not mean that such decisions have to be taken in a data-free environment; choices are not wholly subjective and can be informed by, for example, evidence of what benefits (in particular the value of these benefits) are likely to accrue from particular levels of spending, the opportunity costs of spending on health and social care and comparative benchmarking with spending levels in other countries and regions. Spending levels will also be informed by the values society wishes to pursue - for example, equal access for equal need in health and social care will not only imply a particular distribution of spending within Northern Ireland, but different levels of funding overall in comparison with other parts of the UK.

Secondly, while total funding levels - the *inputs* to health and social care - are important, of even greater significance are the *outcomes* from the system as experienced by patients and the population at large; if the system is inefficient at maximising outcomes for a given level of inputs, then it is not only money that is wasted, but lives too.

Bearing these issues in mind, the broad question we address here is: given multiple calls on limited public sector funding, what should Northern Ireland reasonably expect to devote to its health and social care system now and in the future?

Our approach has been to firstly adopt the assumptions and 'vision' underlying the original Wanless models used to produce spending paths for total (and NHS) spending paths into the future. Secondly, we have adapted the results from the Wanless Review to produce future shares of these UK totals for Northern Ireland.

The rationale for setting long-term projections of resource requirements holds equally for Northern Ireland as the rest of the UK in terms of allowing more effective long-term planning and management of the health & social care sector.

In projecting the future resource requirements for the UK, the approach of the Wanless Review was to focus on England and then use population uplifts for Scotland, Wales and Northern Ireland to produce a total for the UK. Whilst there are a number of areas where this assumption might be open to challenge, the responses to the Wanless Interim Report did not suggest that such an approach was unreasonable. An option that was considered early in our Review was to populate the Wanless (English/UK) model with Northern Ireland data. However, we were advised that this approach was not feasible, and instead decided to take the

Wanless UK projections as given and apply a range of population share adjustments to estimate Northern Ireland's future resource requirements.

Underlying Wanless's future vision were a number of factors that can be expected to increase the pressure to spend more on the health & social care sector in future years. In addition, whilst it would be unrealistic to assume that as spending increases, such pressures will reduce[20] given historical trends, there are actions that Government can take to ameliorate spending pressures. For example, public health promotion and improving the effectiveness of service delivery.

Key factors which drive the pressure to spend more on health and social care include:

- technological developments and medical advance
- higher expectations regarding the range and quality of health care provided,
- demographic and patterns of morbidity,
- extent to which resources are used efficiently

To these might also be added likely changes (increases) in the *value* society attaches to states of good health, with the implication that if the benefits (health) of the system are valued more highly, then this justifies higher costs (that is, spending)[21]

Although surveys suggest that the public are generally satisfied with the health service in the UK (and particularly in Northern Ireland - 79% satisfaction levels were reported for 2004 compared to 74% for 2003[22]), nonetheless, public pressure on services to provide increased responsiveness and quicker access to more effective care is evident.

Demographic changes over the next twenty years will clearly impact on demand for health and social care spending. However, as Wanless and others have noted, the relationship between need for health and social care and, for example, the proportion of the population who are elderly is not straightforward. Although those aged over 65 are among the main users of health services, it is proximity to death rather than age per se which is more important in modelling future health care costs. In terms of the sorts of health and social care problems services will have to deal with over the next twenty years, then the likelihood is that these will remain largely similar in type and scale to those they face now but in line with downward trends in overall mortality.

Although technological and medical advances may in some cases lead to reductions in unit costs, in general it is expected that by allowing more people to be treated for a wider range of conditions (and for a longer time and more effectively) these advances will put upward pressure on costs. Whilst there is considerable uncertainty regarding the future uses of existing technologies, as well as those that have yet to emerge, there is no reason to believe that the trend over the past thirty years (when

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[20] Although this runs counter to the assumption at the institution of the NHS in 1948 that resource requirements would fall as the population became healthier.

[21] Jones CI (2002) Why have health expenditures as a share of GDP risen so much? NBER working paper 9325.

[22] DHSS&PS Public Attitudes to Health and Personal Social Services in Northern Ireland 2004

a significant proportion of the increase in health care costs was due to technological improvements) should not continue.[23]

The improved standard of care expected by public and patients will require a significant increase in the number of health care professionals. In addition, the roles and responsibilities of health care professionals will change, with changes in the skill mix within professions and changes in roles between professional groups.

2.3.3 Wanless expenditure projections for the UK

The projections of future health service resource requirements set out in the Wanless Review were based on the achievement of improved health services in the UK, with a high level of clinical standards to meet the rising expectations of patients and the public.

Some of the main costs of achieving this vision and identified by Wanless include:

> **National Service Frameworks**: Whilst the present reality was considered to be far from this vision, it was anticipated that the NHS Plan will bridge this gap. A key element of the NHS Plan is delivery on the National Service Frameworks (NSFs) which set out national standards for service delivery. There are NSFs in place in England for the following areas; coronary heart disease, cancer, renal disease, mental health services and diabetes.
>
> The Wanless Review projected that an additional £12bn would need to be spent by 2022/23 to deliver the NSFs for these areas. In addition, in recognition that the Government intends to extend the NSF approach to other disease areas it was assumed that similar growth in expenditure would be required to bring service in these areas up to and maintain the required standard. The cost of introducing NSFs to Northern Ireland would depend to a large extent on the level of morbidity for particular diseases and the current level of service provision and organisation.
>
> **Clinical governance**: In order to provide continual improvements in the quality of service provided it is necessary for health care staff to have additional "protected time" devoted to clinical governance structures and schemes. The Wanless Review assumed that all healthcare staff will need to devote 10 per cent of their time to clinical governance compared to the current position of 5 per cent for medical staff and 2 per cent for other professional staff. Whilst this will increase costs in terms of additional staff it will also reduce hospital acquired infections, adverse incidents, avoidable emergency admissions and clinical negligence claims so that the additional net cost across the UK would be around £1.4bn by 2022-23.
>
> **Fast access:** whilst waiting times in England are significantly lower than in Northern Ireland, the view of the Wanless Review was that substantial additional activity and hence resources would be required to match the outcomes in the best performing comparator countries. Overall it was estimated

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[23] The general view of those who were consulted as part of the Wanless Review was that the nature, scope and pace of technological advance in the next ten years will not look radically different to the past ten years- P 173 on Wanless Interim Report.

> that around an additional £12bn would need to be spent by 2022-23 to deliver such improvements.

In addition, given uncertainty regarding the impact of cost drivers such as the health needs and demands of the population, technological developments and workforce issues, and in particular the achievement of assumed productivity improvements, the Wanless Review built up three scenarios:

> ***'Solid progress*** – people become more engaged in relation to their health: life expectancy rises considerably, health status improves and people have confidence in the primary care system and use it more appropriately. The health service is responsive with high rates of technology uptake and a more efficient use of resources;
>
> ***Slow uptake*** – there is no change in the level of public engagement: life expectancy rises by the lowest amount in all three scenarios and the health status of the population is constant or deteriorates. The health service is relatively unresponsive with low rates of technology uptake and low productivity; and
>
> ***Fully engaged*** – levels of public engagement in relation to their health are high: life expectancy increases go beyond current forecasts, health status improves dramatically and people are confident in the health system and demand high quality care. The health service is responsive with high rates of technology uptake, particularly in relation to disease prevention. Use of resources is more efficient.'

It is worth noting here (and for reference in section 3.7 on efficiency) that the Wanless Review made assumptions about improvements in productivity in health care and which underpinned its final spending projections. Table 2.2 details the productivity assumptions made by Wanless and which, given this present Review's approach to projecting spending for Northern Ireland, also underpin our future funding requirements.

Table 2.2: Breakdown of productivity assumptions, per cent a year

	Unit cost reduction		Quality improvement		Quality-adjusted productivity	
	Lower	Higher	Lower	Higher	Lower	Higher
2003/04 - 2007/08	0.75	1	0.75	1	1.5	2
2008/09 - 2012/13	0.75	1.25	0.75	1.25	1.5	2.5
2013 - 2017/18	1	1.5	0.75	1.5	1.75	3
2018/19 - 2022/23	1	1.5	0.75	1.5	1.75	3

Source: Wanless Review Final Report

Wanless identified two components of productivity - cost-reducing and quality-improving. Over the twenty year period to 2022/23, feasible average annual quality-adjusted productivity improvements were assumed to lie between 1.5% and 3%.

Bringing together these scenarios, assumptions and vision for health services in the future through models to estimate, for example, activity needed to sustain very short waiting times, provided some broad estimates of possible spending levels for health care into the future for the whole of the UK (see table 2.3).

Table 2.3: UK Health Spending projections from Wanless Review

	2002-03	2007-08	2012-13	2017-18	2022-23
Total NHS Spending (£ billion 2002-03 prices)					
Solid Progress	68	96	121	141	161
Slow Uptake	68	97	127	155	184
Fully engaged	68	96	119	137	154
Average annual real growth in NHS spending (per cent)[1]					
Solid Progress	6.8	7.1	4.7	3.1	2.7
Slow Uptake	6.8	7.3	5.6	4.0	3.5
Fully engaged	6.8	7.1	4.4	2.8	2.4

Source: Wanless Review Final Report
Note: Growth figures are annual averages for the five years up to date shown (four years for 2002-03)

The table shows that under all scenarios the greatest growth in resources is required in the first ten years of the projections, as the UK ‘catches up’ with its European neighbours, with slower growth thereafter. As would be expected, the Fully Engaged scenario has the lowest cost whilst the Slow Uptake has the highest.

2.3.4 Application of Wanless projections to Northern Ireland

In estimating the long-term sustainable resource requirements of the health & social care sector in Northern Ireland, the approach involved taking the Wanless spend projections for the UK and estimating Northern Ireland’s need-adjusted share (see Annex D for further details). A key (and acknowledged) gap in the Wanless work was the exclusion of projections for social care services. With no future estimates for social care spending across the UK, for Northern Ireland projections it is assumed that social care receives increases in funding similar to health care.

There has been considerable debate as to Northern Ireland’s “fair share” of any growth in UK/England spend. Therefore, this analysis presents a range of outcomes based on alternative models embodying differing views as to the quantum of the fair share.

Our approach implies a set of criteria or objectives for the distribution of resources under devolution. In particular, that each country should receive resources that would *enable* it to provide the same standard and mix of services as the average for the UK as a whole, independently of local ability to pay. Whether an individual country chooses to provide higher or lower standards or a different mix is purely a local policy issue. It has long been accepted that differences in need will affect the cost of providing equivalent services and therefore must be incorporated into an estimate of “fair shares”. An implication of this approach is that the relevant “needs” factors and their weights must be those applied to the UK as a whole.

The main problem with this approach is that there is no pan-UK derived allocation formulae - that is, one using UK data to construct the appropriate weights for needs factors. However, there are a number of allocation formulae - for individual parts of the UK , for example - which we examine in our analysis. However, it must be emphasised that in the absence of a UK-wide formula based on appropriate UK data, choosing between the results of our modelling work is, for now, more a matter of judgement than empirical fact.

Under current public sector funding mechanisms for the devolved administrations, changes in English spending departments' allocations drive changes in allocations in Scotland, Wales and Northern Ireland - primarily on the basis of population via the Barnett Formula as discussed in section 2.2. For example, as Northern Ireland's population is currently 3.4% of that in England, an increase in English public expenditure of £100m translates into an increase of £3.4m for Northern Ireland. There has been concern in Northern Ireland that the Barnett Formula is intrinsically unfair because it takes no account of the relative need for expenditure. In addition, the out workings of the Formula mean that when a Devolved Administration has a higher level of public expenditure per head of population than England (as is currently the case for Scotland, Wales and Northern Ireland), the growth in expenditure is lower than in England.

On this basis it is argued that Northern Ireland should receive funds *in addition to its population share*. In previous years, this has been accomplished through 'formula bypass', where Northern Ireland was allocated additional funding for specific areas - although more recently HM Treasury has adopted a stricter approach to the application of the Barnett Formula. As a result, Ministers in the previous Northern Ireland Executive lobbied for a review of the Barnett formula with a view to adopting a needs-based approach. On this basis, in the example above, if Northern Ireland's per capita need for expenditure was agreed to be10% higher than in England then it should receive an additional £3.74m.

Of course, critical in this respect is the extent to which the need for expenditure is actually higher in Northern Ireland than England. In 1979, and as part of preparations for greater devolution, HM Treasury conducted a Needs Assessment Study (NAS) to develop a model to estimate the public expenditure need factor (with England =1) for Scotland, Wales and Northern Ireland across a range of public services - including health and social services - although the analysis was never formally agreed. The NAS model was based on a weighted average of a range of factors including age structure, morbidity, deprivation, rurality and other cost drivers, and is in some ways comparable in approach to current weighted capitation allocation formulae used in England, Northern Ireland, Wales and Scotland to allocate NHS global budgets within countries.

In 2001, the Northern Ireland Executive commissioned a series of Needs and Effectiveness Evaluations (NEE) for five public expenditure areas. A significant part of each study was to update, where available, the existing HM Treasury NAS model and suggest evidence-based changes to the construct of the model. Whilst the results of the needs element of each study have not been published, the details of the models have been made available to this Review and updated for the latest available data. Three basic scenarios had been developed as part of the 2002 NEE:

> **NAS Update** - based on updated data to populate the HM Treasury Model, this implies a need indicator of **1.0395** for the latest available data - that is, given the relative difference in the need for health care (based on factors such as

population structure and mortality) Northern Ireland should spend **3.95%** more per head of population on health services than England.

NI Executive Update - based on changes to the *structure* of the model, in particular, greater weight given to deprivation factors where Northern Ireland's need relative to England is high. This implies a need indicator of **1.132 (+13.2%)** for the latest available data.

NI Executive+ Update - based on the NI Executive update plus additional adjustments where the supporting evidence is less robust. These include adjustments to take account of differences in the ability to pay, private provision and community tensions. Overall, this implies a need indicator of **1.165 (+16.5%)** for the latest available data.

In addition to these modelling approaches, this Review has also looked at four further potential methods for arriving at a fair share for Northern Ireland of the Wanless UK projections:

EQ-5D health status model: The needs assessment models detailed above use a number of proxy variables for the need for expenditure on health & social care services which in reality relate primarily to the incidence of illness in a given population. The reason such proxy indicators are used is that there is generally very little data collected on the real factor of interest - *health*. However, the EQ-5D survey on health status discussed in Section 3.2.2 provides a direct measure of health status which can be compared with similar information for England. The results of the EQ-5D survey indicate that the average level of self-reported health in Northern Ireland is approximately 96% of that in England, implying a need indicator of **1.04 (+4%)**. This makes the strong assumption that there is a one to one relationship between the relative EQ-5D score and the need for spending.

A number of approaches were also considered based on the application of Northern Ireland data to the needs-based formulae for allocating health funding *within England, Scotland and Wales*. Unfortunately it was not possible, due to lack of available data, to use the models for Wales and Scotland, whilst the results set out below based on analysis carried out by DHSSPS using Northern Ireland and English allocation methods are subject to a number of caveats.

Northern Ireland allocation model: DHSSPS have populated the allocation formula for Northern Ireland with the latest data for England. This resulted in a set of need indicators for 11 programmes of care (POC) which ranged from **0.867 (-13.3%)** for the Elderly POC to **1.711 (+71.1%)** for the Physical & Sensory Disability, whilst Acute Services had a need indicator of **1.041 (+4.1%)**. Overall, the basic need indicator across all POCs was **1.095 (+9.5%)**. There are additional factors that are not material in an internal Northern Ireland formula but are significant when comparing with England. Including adjustments for rurality (+0.027) and resource costs increases the need indicator to **1.116 (+11.6%**)

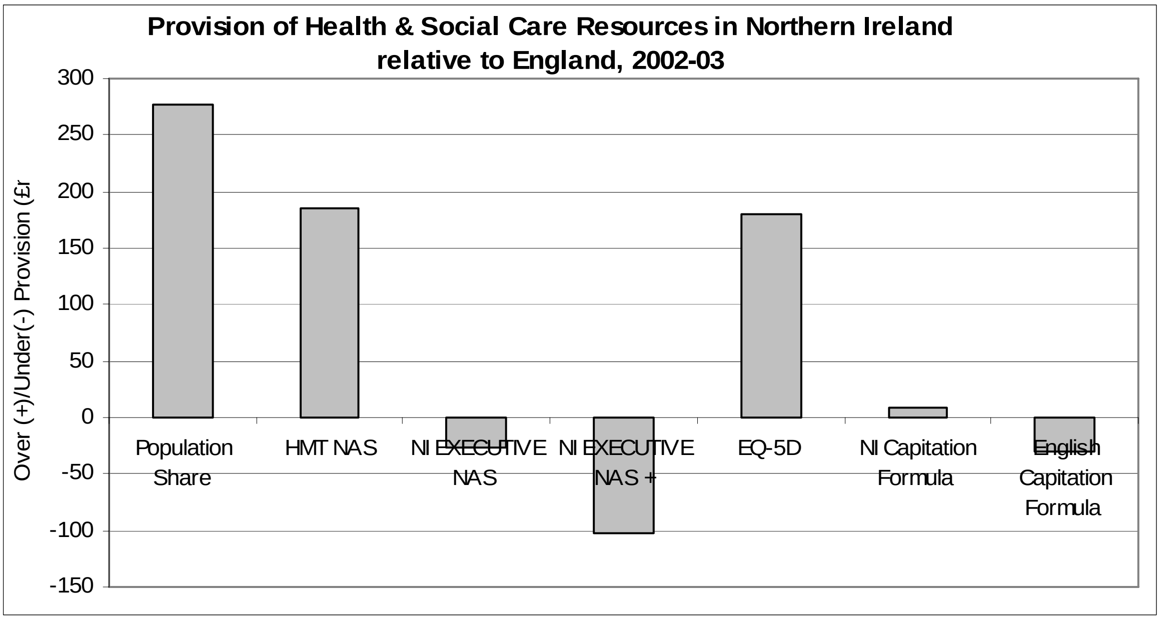
English allocation model: DHSSPS have also populated the allocation formula for England with the latest available data for Northern Ireland. The analysis was restricted to expenditure covered by hospital and community health services (HCHS) which accounts for approximately 77% of total spend. The main omission was social services which, if included, would have been expected by DHSSPS to increase Northern Ireland's relative level of need. The overall Northern Ireland age-need indices for Acute/Geriatric/Maternity and Mental Health are **1.065 (+6.5%)** and **1.541 (+54.1%)** respectively which translates into an overall need indicator of **1.133 (+13.3%)**.

International benchmarking: In order to provide a slightly different perspective - although one which in part reflects the Wanless Review's perspective concerning 'catch up' and 'keep up' - linkage between national per capita income and per capita health expenditure, which can be seen in an international context, was considered. Although the direction of causation may flow both ways, it is useful to estimate the level of health expenditure that Northern Ireland could afford given its level of economic activity without external financial support. On this basis, relative levels of economic activity (GDP) per head would suggest that Northern Ireland could only afford to spend 77% of the English level per head of head of population on public services.

Throughout the consultation process a consistent theme has been that health and social services in Northern Ireland are under-funded, and that, for example, initiatives in England cannot be replicated locally because of insufficient funds related to the lower growth in spend, or that activity growth necessary to tackle waiting times problems cannot be generated, again due to lack of funds.

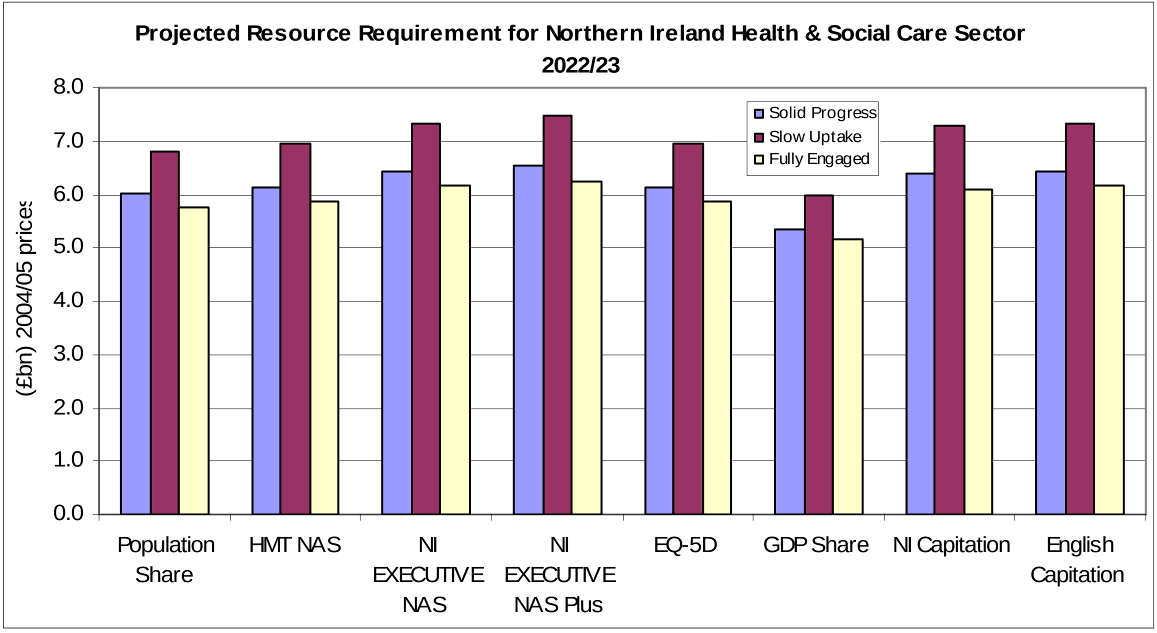
In order to assess the current position, figure 2.17 shows the results of applying each of the above spending models to the 2002/03 level of health & social care spend in Northern Ireland relative to England. For 'status quo' comparison, the figure also includes estimates based on application of the Barnett formula ('population shares'). It can be seen that the estimates range from an over provision of £276m, to an under provision of £103m. In addition, on the basis of its level of economic activity relative to England, it is estimated that expenditure on Northern Ireland's health & social care sector should be £800m *lower* than the current level (not shown on the figure). It should be noted however that these comparisons are based on HM Treasury figures which indicate that spend on health and social services per head of population is significantly higher in Northern Ireland than England, whilst it is the view of DHSSPS that there is parity in spending levels. The Review has been advised by DFP that as National Statistics, the HM Treasury figures should take precedence.

Figure 2.17: Estimates of Northern Ireland's current HPSS spend range from underprovision of £103 m to an over provision of £276 m.



In examining future trends in spending, one option was to assume that under a needs-based approach, the adjustment would be applied to all expenditure initially, with the same growth in spend as England thereafter. However, this would have been unrealistic, as with some models which have suggested current overprovision, the changes in expenditure would have placed substantial resource pressures on the system. Instead, as with the Barnett Formula, the needs-based adjustment is assumed to apply *only to additional spend*. Figure 2.18 therefore sets out the range of projections for the resources required for the health & social care sector in Northern Ireland in 2022/23 under different modelling scenarios.

Figure 2.18: Wanless-based 2022/23 resource requirements suggests variations in spending under different modelling scenarios



Under the Solid Progress scenario, projected spending for 2022/23 ranges from £5.3bn to £6.5bn; That is, a real increase over twenty years of between £2.7bn to £3.9bn. Under the Slow Uptake scenario, additional resources of £3.3 to £4.8bn would be required, whilst under the Fully Engaged scenario additional real spending of £2.5 to £3.6bn would be required. However, as figure 2.19 shows, a significant increase in resources is projected compared to historic trends regardless of the assumption on relative need.

Figure 2.19: Although there is some variation in projected expenditure, all scenarios continue the significant growth in HPSS spend.

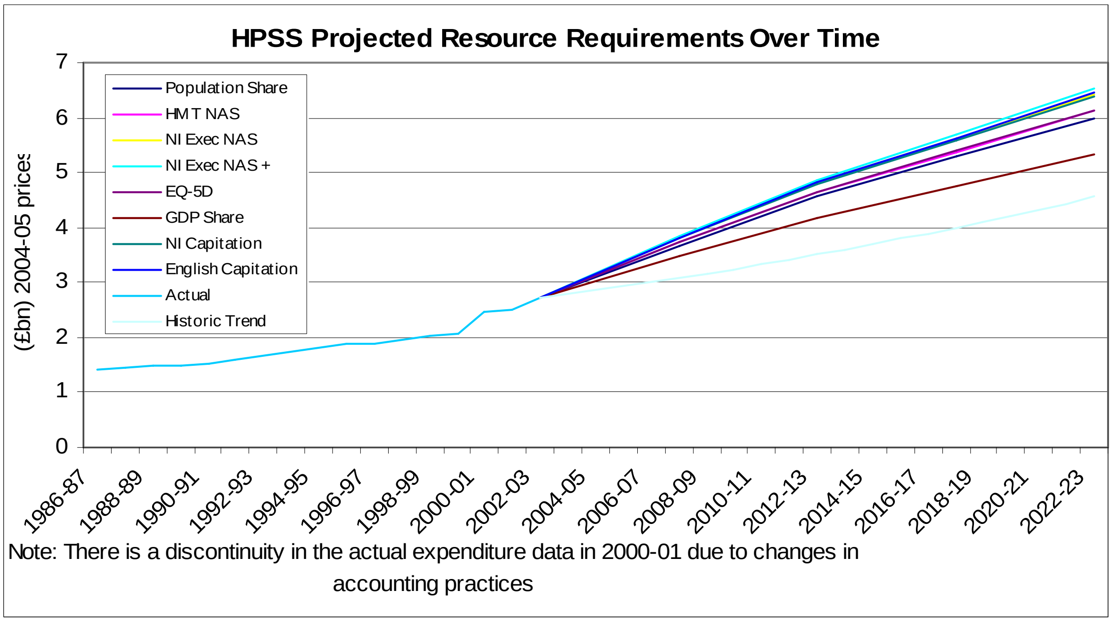
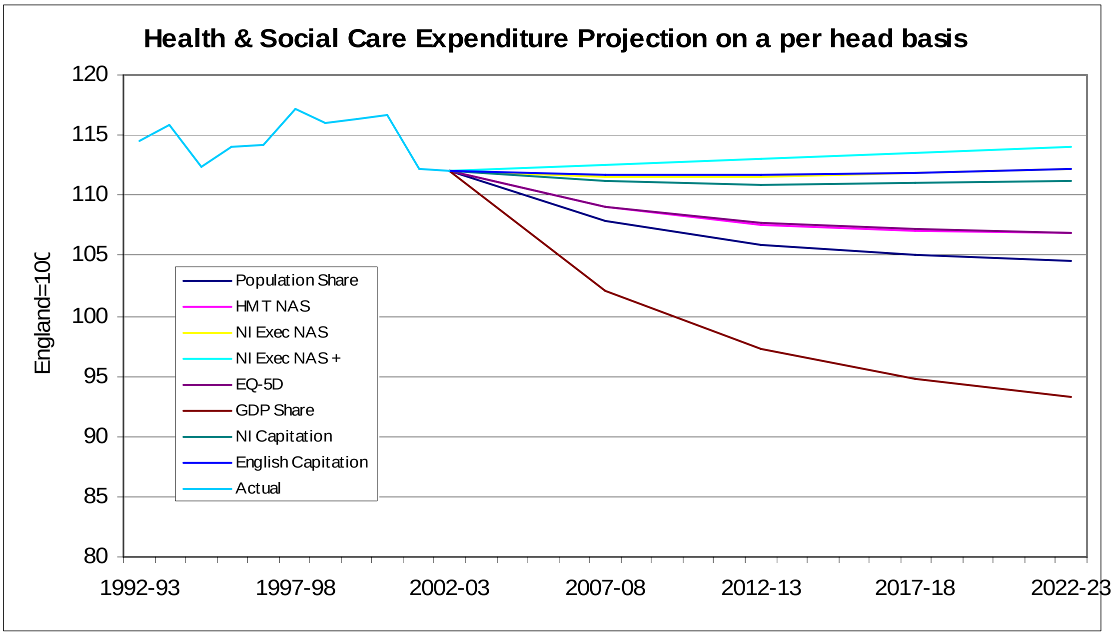


Figure 2.20 sets out the overall spend figures translated into spend per head relativities between Northern Ireland and England. If the assumed difference in need is greater than the 2002-03 difference in expenditure per head between Northern Ireland and England then expenditure per head relative to England is projected to rise over the next twenty years. It can be seen under the Northern Ireland Executive version of the NAS model with additional adjustments, spend per head is projected to rise to 114% of the English level by 2022-23 whilst under the GDP share scenario spend per head falls to 93% of the level for England. Under the Barnett formula spend per head is 4.6% higher than in England by 2022/23.

In many ways, these are somewhat pessimistic projections as, even under the Wanless 'fully engaged' scenario, they assume a continuation of the gap in relative need between Northern Ireland and England. It would be hoped that given efforts to meet the requirements of the fully engaged scenario, in the longer term the relative need gap would reduce.

Figure 2.20: Expenditure projections imply that Northern Irelands spend per head on Health and Social Services will range from 6.8% below the level in England to 14.1% above by 2022-23.



Although a range of estimates are set out above, it is important that the Review expresses a view as to which is the most appropriate.

International benchmarking (GDP share)

In its current constitutional state there is only a limited link between the amount of revenue raised by the Government in Northern Ireland and the subsequent expenditure on public services in the region. Therefore, the scenario based on a GDP share has been included for illustrative purposes only and does not represent a serious possible outcome.

EQ-5D health status model

Intuitively, sharing out health care resources on the basis of differences in population's health status is not only a more direct method than using proxies for health status, but a better approach too. Figure 2.21 below shows that there is a reasonably strong relationship between standardised EQ-5D scores for Strategic Health Authorities (SHAs) in England for 2003/4 (derived from the 2003 Health Survey for England) and SHA weighted capitation allocations (based on mortality and deprivation weighted populations) adjusted for differences in the cost of living, with a correlation coefficient of around 0.70 and an R^2 of 0.49[24]. In other words, variations in health explain around 49% of the variation in per capita funding between English SHAs.

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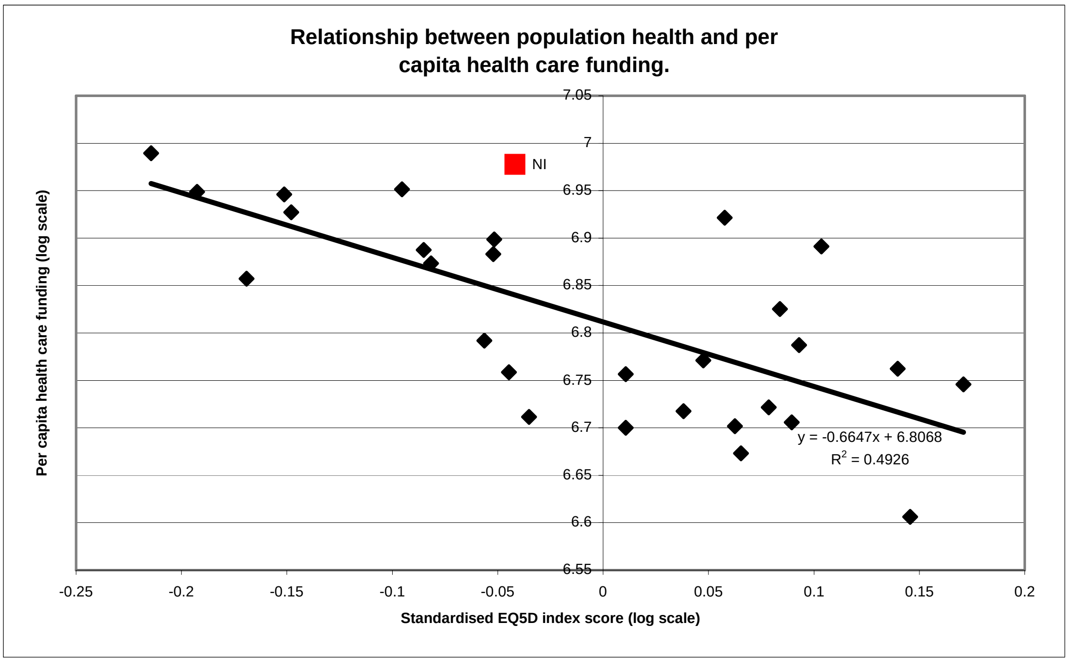
[24] Including a dummy variable to take account of two outliers (North Central and North West London) further increases the R^2 to 0.68.

Figure 2.21: Northern Ireland receives significantly higher levels of health spending per head of population than would be expected given its health status relative to English SHA's.



In terms of funding implications, the trend line slope coefficient of 0.6647 suggests that the 4% poorer (self reported) health status in Northern Ireland relative to England should translate into a 2.8% higher level of spend per capita - considerably less than is the actual situation now.

This model is, however, simplistic, and could no doubt be improved with further work and the addition of other variables. As it stands, and even though there is an argument that the EQ-5D data is better than the available evidence on morbidity, judging Northern Ireland's relative expenditure need on the basis of relative needs as reflected by overall standardised EQ-5D scores provides at best a guide to spending. In the results summarised in figures 2.17-2.20 we have assumed a one to one relationship between EQ-5D score and spending.

Barnett Formula (Population shares)

The population share or Barnett Formula approach reflects current Government policy for funding Scotland, Wales and Northern Ireland. A key weakness of the Barnett formula is that it does not take into account the differing needs for expenditure between areas. Whilst Barnett might have been useful in the past as a means of narrowing the gap in levels of spending per head between UK countries (and acting as a rough rule of thumb to, in Joel Barnett's view, curtail wrangling over allocations) there is an argument for a more sophisticated approach to be adopted. All countries of the UK distribute the funding for services within their borders on the basis of needs-adjusted formulae; It is not clear why this principle cannot be extended to the allocation of funding between UK countries.

Northern Ireland allocation model

Populating the Northern Ireland allocation model with English data produced an overall basic need indicator across all POCs of **1.095 (+9.5%)**. However, this result is very sensitive to the need estimates for just two POC's (Learning Disability, and Physical & Sensory Disability) which together account for less than a tenth of overall spend. If the indicators for these POCs are set to one, then the overall need indicator falls to 1.04.

The very high relative level of need for these two POCs appears to be driven to a considerable extent by relative levels of benefit receipt. For example, a key driver for Physical & Sensory Disability is the percentage of 16-64 year olds in receipt of Disability Living Allowance, which is 141% higher than in England, whilst the proportion of people with a long-term illness is only 34% higher. Setting the benefit receipt element of the model to zero reduces the need indicator from 1.711 to 1.155 for this POC.

Moreover, given this model's implicit argument that there is much greater need for spending in the areas of learning, physical and sensory disabilities, it would be expected that this higher level of need would be reflected in a higher level of relative spend for these POCs. However, whist the need for expenditure in these two POCs is estimated jointly to be 63% higher than in England, the actual level of expenditure is only 36% higher. This is also the case with respect to the Mental Health POC, where need is estimated to be 43% higher, but actual spend per head is the same as in England[25]..

English allocation model

As with the Northern Ireland allocation model, the results of populating the English weighted capitation formula with data from Northern Ireland are sensitive to changes in a small number of factors. For example, in respect of the Acute/Geriatric/Maternity index, one element - the circulatory system morbidity factor - is based on 2001 data which indicates that Northern Ireland has a 7.3% higher rate of death from this group of diseases than England. However, between 2001 and 2003 the number of deaths from diseases of the circulatory system has continued to fall at a faster rate in Northern Ireland than England and Wales so that the gap is projected to have fallen to 3.4%[26]. On this assumption, the respective need indicator falls from 1.065 to 1.045.

The same principle applies to an even greater extent with respect to the mental health indicator which, at 1.541, is elevated by an estimate for a psycho-social morbidity index which was proxied using Northern Ireland survey data indicating that the proportion of those aged 16+ showing signs of possible mental health problems was considerable higher than in England. However, the EQ-5D survey carried out for this Review shows, for example, that mental health status in Northern Ireland is actually better than in England[27]. If this assumption is applied to the model then the mental health need indicator falls to 1.10.

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[25] Spend data taken from the 2002 Needs and Effectiveness Evaluation.

[26] The number of deaths caused by circulatory diseases fell by 6.5% in Northern Ireland over the period 2001-2003 compared to 3.0% in England & Wales- Table 9.6 Annual Abstract of Statistics.

[27] The proportion of respondents to the Northern Ireland EQ-5D survey (2005) reporting any problem with anxiety/depression was 15.2%; the equivalent proportion for England in 2003 was 19.2%

The need indicator quoted in applying Northern Ireland data to the English Capitation Formula does not include a market forces factor to take account of variations in the unavoidable cost of providing healthcare. Whilst it has not been possible to estimate a comparable market forces factor for Northern Ireland, data is available from National Statistics indicating that the cost of living is around 5% lower than in England.

Overall, adjusting for more recent changes in deaths from circulatory diseases and the differential cost of providing services has the impact of reducing the overall need indicator - based on the allocation formula for England - from 1.14 to 1.07.

DHSSPS have indicated, however, that these models do not include a number of factors that are relevant when comparing the relative need between Northern Ireland and England. For example, taking account of additional costs incurred in supporting services in areas of high community tension as well as the lower level of private provision in Northern Ireland compared to England increases the overall need indicator by 0.02.

It has not been possible in the time available to carry out the level of critique required to come to a final position on the relative level of need for health & social care expenditure in Northern Ireland relative to England based on the respective allocation formulae. Therefore, the results of applying these models (set out in figure 2.17-2.20) are based on the results of the initial update provided by DHSSPS.

Overall, therefore, whilst on first sight the capitation formulae for England and Northern Ireland would suggest that spend per head should be 10-14% higher in Northern Ireland, the results are highly sensitive to the data used. In particular, changes in the assumptions behind one or two key factors can significantly reduce the overall level of need. Depending on the assumptions used, in particular the choice of data used where no direct substitute is available, the formulae can be used to support the original HMT NAS model or the subsequent revisions made by the Northern Ireland Executive.

HM Treasury NAS Model

Whilst the HM Treasury NAS model has been used to inform funding decisions, it has not been used to allocate resources directly across UK countries, with the continued preference being the Barnett Formula. Since 1979 there have been some small changes in the methodology of the NAS model with the last completed update taking place in 1994.

In the subsequent period there has been a large amount of empirical analysis carried as part of the further development of the internal health resource allocation formulae of the four countries of the UK. In addition, there have been significant changes in some of the socio-economic indicators used in the model which means that it may no longer be appropriate for them to be included. For example, there has been significant progress in terms of housing conditions, with only 0.5% of households in England lacking or sharing the use of bath/shower and/or inside WC, so that it is unlikely to be as important a factor as it has in the past.

The main criticism put forward by the Northern Ireland Executive, however, was that insufficient weight was given to deprivation factors in the HM Treasury NAS model. For example, in the HCHS element of the model mortality has ten times the weight of deprivation. However the latest internal allocation formulae of England, Scotland, Wales in Northern Ireland all place significant weight on deprivation factors although it is difficult to estimate precisely a weighting factor relevant to the NAS model from this work because of differences in the way the formulae are constructed

NI Executive Update and NI Executive Update+ models

The University of York was commissioned to provide an initial assessment of the evidence used by DHSSPS to suggest changes to the HM Treasury NAS model. It was acknowledged that there were weaknesses in the NAS model and that there might be a case for increasing the weight of deprivation in assessing relative need. However, the evidence put forward (including background statistical work) was considered to be insufficiently robust for all the revisions to be accepted in full and that more research would be required for the argument to have sufficient weight to affect a change in the NAS model (see Annex E). These criticisms are endorsed by this Review. However, it should be emphasised that the criticisms relate to the standard of evidence reviewed. It may be that a UK-wide analysis to derive an allocation model could endorse the suggested updates of the NAS model. However, as things stand, it is not possible to endorse all the revisions.

In addition, as with the use of the English and Northern Ireland allocation models, the relative needs estimates obtained from the Northern Ireland Executive updates of the HMT NAS model are very sensitive to just a few health needs proxy variables.

For example, overall the need indicator for the Northern Ireland Executive revised NAS model is 1.132. However, this depends largely on factors relating to the number of Income Support recipients which are present in almost all elements of the model. Setting each of these factors to one reduces the overall need indicator to 1.023.

From a different perspective, at 65%, the differential between Northern Ireland and England in terms of Income Support recipients per head of population in the NAS model appears to be high. Across the UK, Northern Ireland has by far the highest level of Income Support recipients per head of population despite having generally more favorable labour market conditions. For example, the unemployment rate is equal to the UK average of 4.8% and is lower than in London (7.1%) and the North East (5.4%), whilst the number of jobs per resident population is higher than the North East and Wales. As a sensitivity, applying the IS per head relativity for the North East (1.34) to the NAS model results in the overall need indicator falling from 1.132 to 1.0796.

There may be an argument for giving greater weight, however, to the NAS deprivation factors - based on practice in Scotland and England. But, again, the evidence to justify the particular additional weight suggested by the updates is not considered robust.

As noted earlier, in the absence of a UK-wide allocation formula based on UK data to derive appropriate weights for relative needs factors etc, choosing between the models examined above becomes, in part, a matter of judgement.

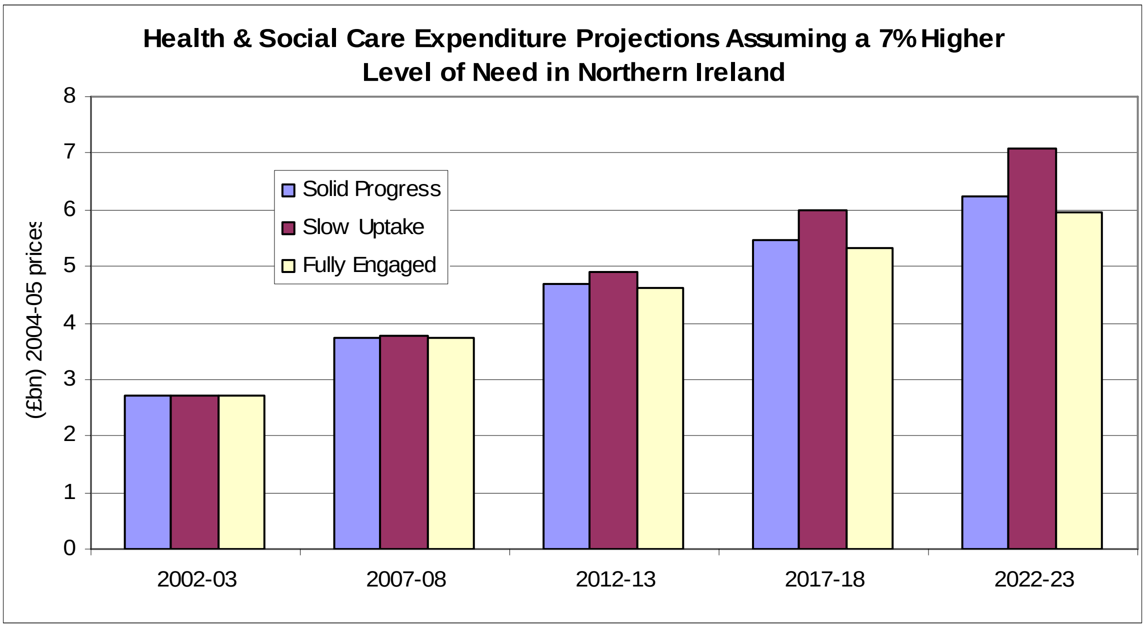
Given the criticisms and uncertainties noted above for the models tested, the two main candidates for a UK-wide formula are the NAS model, originally designed as an attempt at a UK-wide allocation guide, and the English capitation model populated with Northern Ireland data. The choice of the latter is based on the argument that it has relatively a stronger evidence base for the weights it employs and that in a UK-wide analysis to determine needs weights, English data would be likely to dominate, and that hence the current English weighted capitation formula is likely to get close to results that a UK-wide formula might produce.

However, as identified above, it has not been possible to perfectly populate the English capitation formula with Northern Ireland data, and the results are sensitive to changes in some of the factors underlying the model - to the extent that the additional per capita resourcing for Northern Ireland implied by the model could vary between 4% and 14% - the variation driven almost entirely by the very large (+59%) extra spend per head for mental health relative to England implied by the data used to populate this single needs factor.

Given this, the judgement of this Review (to be confirmed or denied in the light of any subsequent results arising from a UK-wide allocation model) is that a reasonable need differential between England and Northern Ireland should be around 7%. This is less than that implied by the English capitation model (due to the high sensitivity of the results from this model from just one needs factor - for mental health). But it is greater than that implied by the original NAS model, allowing for evidence from work carried out on the English and Scottish allocation formulae that the weight given to deprivation factors should be higher than 7.5%.

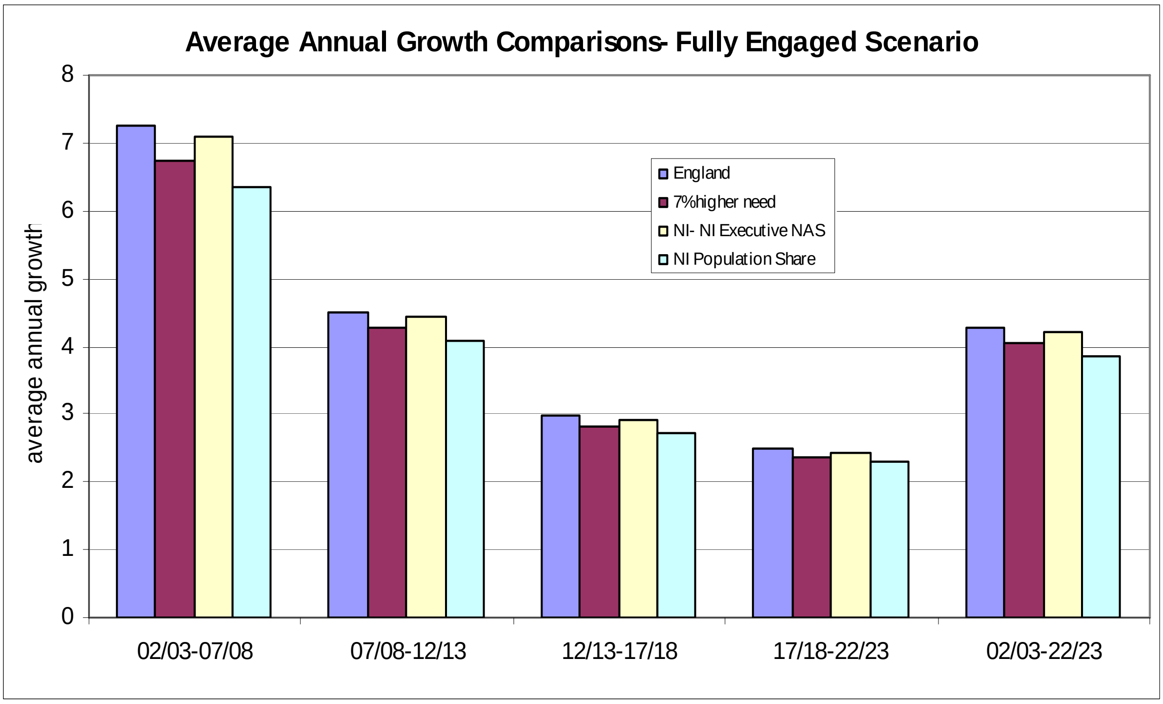
On this basis, the projected resource requirements for the health and social care sector in Northern Ireland over time under this assumed level of need are set out in figure 2.22 below.

Figure 2.22: Assuming a 7% higher level of need suggests real increases in Northern Ireland health and social care spending by 2022/23 of between £3.3bn and £4.4bn - percentage increases of between 121% and 162%



In terms of growth in expenditure, figure 2.23 below shows that there is a small difference in growth rates under the various scenarios, with the baseline position for England. The chart also highlights the extent to which the additional growth occurs in the 2002-03 to 2007-08 period with progressively slower growth in the five year periods thereafter.

Figure 2.23: Average Annual real growth Under the Fully Engaged Scenario is 4.0% for Northern Ireland assuming a 7% higher level of need compared to 4.3% for England.



Recommendation 3: Adopt HMT NAS model-based Wanless 'fully engaged scenario' projections as set out in Table 1 for now as best reasonable guide to future spending in NI.

Recommendation 4: Further work is needed to investigate the usefulness of employing direct measures of health status (for example, as derived from instruments such as the EQ-5D) in resource allocation models.

Recommendation 5: Future work on pan-UK resource allocation model would provide a more empirically-based answer to relative shares of resources. Such work should be open, and draw on extensive experience in the area of resource allocation models of research groups across the UK.

2.3.5 Implications of funding projections for the Barnett Formula

The projections detailed above imply that the health & social care sector in Northern Ireland will require an additional £210m in funding by 2022/23 compared to that which would be expected under the Barnett Formula, given the 7% higher level of need. There are two main mechanisms through which this funding could be secured:

(1) additional resources from HM Treasury (i.e. population share of English increases in spend, equivalent to an additional 7%)

(2) the re-allocation of resources from within Northern Ireland (i.e. reduce expenditure on other public services)

It is clear that option (1) would present significant difficulties for HM Treasury in terms of the potential repercussions for other parts of the UK and for other spending programmes.

The alternative is that the additional funds required for health & social care, over and above that received in the form of the respective Barnett consequentials, are obtained by diverting resources from other spending programmes within Northern Ireland. Under this scenario, for health spending per head to be 7% higher than in England would require spending in all other spending programmes to be 5% lower than in England, equivalent, for example, to a 15% fall in the Department of Education budget[28].

Such an outcome is clearly inconsistent with the "…long established principle that all areas of the United Kingdom are entitled to broadly the same level of public services and that the expenditure on them should be allocated according to their relative needs"[29]. In addition, the implication of the Barnett Formula - that public spending per head should be equalised across the UK - does not apply to the current position

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[28] Alternatively if spending on schools was assumed to be in line with relative pupil numbers then spending in the rest of the NI departments would need to fall by almost a quarter.

[29] Para 2.9 Needs Assessment Study Report. The Report of an Interdepartmental Study co-ordinated by HM Treasury on the Relative Public Expenditure Needs in England, Scotland, Wales and Northern Ireland HM Treasury (1979)

within England where, for example, identifiable public expenditure is 15% higher per head of population in the North East than England as a whole[30].

Whilst additional work is required to assess with greater precision the UK wide variations in need for health and social funding, as an initial position it is the view of this Review that the second option for funding the spend projections detailed above are not feasible and are inconsistent with the parity of provision principle. Therefore, there should be some form of Barnett formula bypass, as has been the case in the past, to allow the same level of service to be provide in Northern Ireland as the rest of the UK.

> **Recommendation 6: If the future spending path suggested by this Review is accepted, then there needs to be some way round the implications of the Barnett Formula for health and social care if the general principle of Barnett are to be maintained and other public services in Northern Ireland are not to suffer.**

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[30] 2004/05 figures from Table 8.11 in PESA 2005 (HM Treasury)

3: Health and Social Care in Northern Ireland Today

3.1 Introduction

The previous section provided an overview of current health and social care funding and allocations in Northern Ireland, and used the approach to future funding employed by the first Wanless Review to suggest a set of future spending paths for health and social care services. These implied a more than doubling in real terms of funding over the next twenty years. But setting the broad budget parameters only tackles part of the task of delivering a high quality health and social care service; health care needs, how services are used and the efficiency with which services are delivered all combine to determine the quality of the outcomes services can produce.

This section therefore reviews the implied demand for health and social care services arising from the current state of health of the Northern Irish population, the actual demand as revealed by the use of services and, crucially, the extent to which health and social care resources are currently being used effectively to address needs and provide acceptable levels of access to services.

In particular, we cover in some detail issues concerned with waiting lists and times, efficiency and productivity and workforce and pay.

Section Conclusions

In considering the health & social care system in Northern Ireland there has tended to be little analysis of performance, with the main emphasis being on funding as the main determinant of outcomes such as waiting times. Whilst to an extent this is understandable given the difficulty in measuring the efficiency with which public services are delivered, it is vital that the performance of the health & social care sector is monitored in support of a rigorous performance management system.

In this section, the performance of the Northern Ireland health & social care sector is compared with the rest of the UK across a range of indicators, collectively providing a broad indication of relative performance. In terms of waiting times the picture is unambiguous, with Northern Ireland having significantly longer waits than the rest of the UK. It is important to recognise however that there are significant variations within Northern Ireland between trusts and between specialties, with some areas making significant progress whilst in others, performance is less impressive. Therefore, long waiting times can be reduced by adopting a long term strategy, including long term targets backed by strong incentives,

Activity levels per head of population in Northern Ireland hospitals are found to be broadly similar to the rest of the UK, although A&E attendances are significantly higher, raising questions regarding demand management. In addition, given that there are significantly more resources used in the provision of health care in Northern Ireland, this implies that efficiency is lower in terms of inputs such as staff and beds as well as overall funding. Whilst the lower level of efficiency may in part be due to factors considered legitimate - such as the provision of services in rural or deprived areas - the full opportunity cost of such policy decisions needs to be fully appreciated.

In terms of staff, despite a general perception to the contrary, Northern Ireland appears to be reasonably resourced in a UK context with significantly higher levels of staffing than in England. In addition, the local labour market for health and social care staff appears to be relatively benign in terms of the recruitment and retention of staff with lower vacancy rates, use of international staff and cost of living whilst there is a larger public sector pay premium than is the case for the other UK regions. In terms of the Governments policy on public sector pay and the significant financial implications of recent pay reforms in the health sector, the continued maintenance of pay parity with the rest of the UK needs to be re-examined.

The issue of pay was also found to be relevant in terms of Family Health Services where it was not clear that the new payment contracts represented value for money. The relationship between GP's and the rest of the health & social care system appeared to be somewhat disjointed as a legacy from fundholding. In addition, despite implementing various initiatives to reduce the problem, Northern Ireland still has a significantly higher level of spend on prescription drugs per head of population than the rest of the UK. As with the rest of the health & social care sector this can be linked in part to the absence of sanctions to discourage poor performance.

Social services is the area of the health & social care system where provision in Northern Ireland is considered to be the furthest behind that in England. Whilst the available evidence suggests that this is not necessarily the case, Northern Ireland still appears to be many years behind in England in terms of achieving the policy aim of providing social services in a community rather than hospital environment wherever possible. In addition, despite having lower unit costs than in England, there appears to be scope for services to be delivered more efficiently.

3.2 Health

The health of any population is a complicated function of many economic, social, cultural, lifestyle, educational and other factors, as well as the level and consumption of health and social care services, provided and used over people's lifetimes. Although there is a conventional wisdom that health and social care contribute only marginally to improvements in population health, it is now increasingly recognised that once the big breakthroughs in public health measures have been achieved - proper sanitation, good housing, universal education and so on - organised health and social care services, at the margins, have a substantial impact on improvements in life expectancy and other measures of health.

While, in part, improvements in populations' health is attributable to the provision of health and social care services (and provide an indication of the success or performance of services), care needs to be taken in interpreting changes in, or comparative levels of, health either in terms of success or in terms of failure to fully meet needs (with the implication that too little is being spent on services).

Here we provide an overview of broad measures of the health of the Northern Irish population and report on a survey of a sample of the population carried especially for this Review and investigating people's self-reported health.

3.2.1 Mortality

Age-standardised mortality rates per 100,000 population in Northern Ireland are comparable to Yorkshire and Humberside and around 2.4% higher than for the UK as a whole (figure 3.1). Although cancer mortality rates are lower than the UK average, Northern Ireland has significantly higher rates for respiratory diseases and the highest mortality from road traffic accidents. Infant mortality is also now close to the UK average having fallen from 13.2 per 1,000 live births in 1981 to 5.3 in 2004.

An issue that arose in the Review's consultation process was the assertion that the high number of suicides in Northern Ireland was a reflection of broader general mental health problems - and by implication, a need for greater investment in mental health services. However, mortality rates from suicides match the UK average.

As in many countries, however, over time, overall mortality in Northern Ireland has been falling. In fact, between 1996 and 2001, death rates have fallen by nearly 14% - faster than for the UK as a whole (9%)[31].

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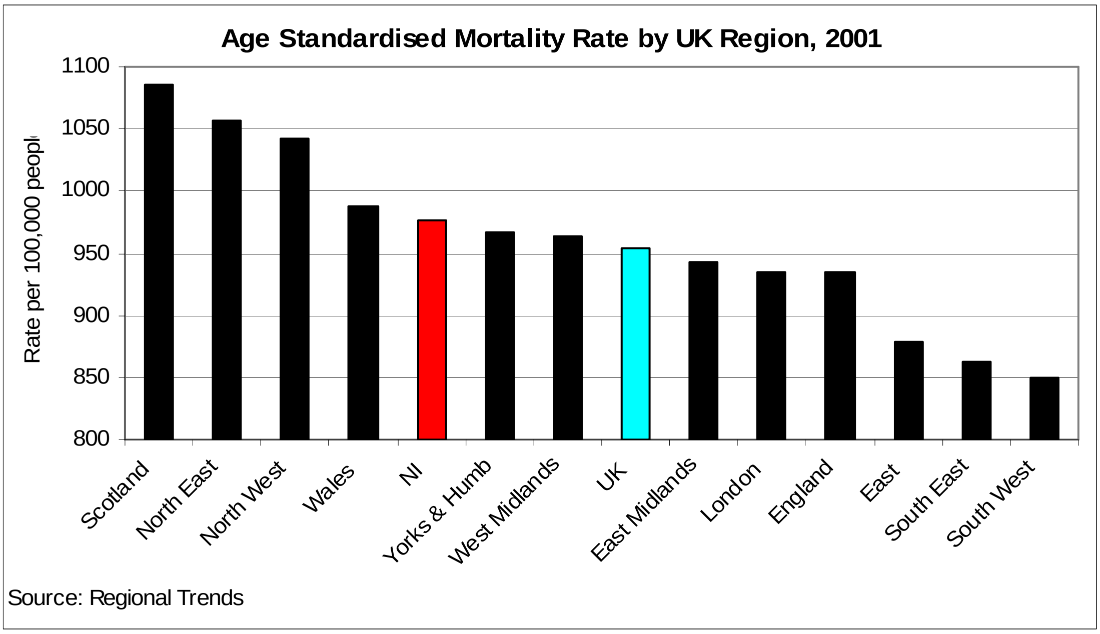
[31] However, in a historical context, during the 1960's NI had the lowest level of mortality of any UK region (Bardon J, A History of Ulster)

Figure 3.1: The age standardised mortality rate in Northern Ireland is 2.4% higher than the UK average in 2001



Source: Regional Trends

Falling mortality rates means that life expectancy improves. And over the last twenty years life expectancy at birth in Northern Ireland has increased by 4.2 years for females and 6 years for males - although females (80.6 years at birth) continue to have a significantly higher life expectancy than males (76.0).

Figures 3.2 and 3.3 show that over the past two decades life expectancy for both females and males has grown at a faster rate in Northern Ireland than the other constituent countries of the UK with the result that life expectancy is now higher than Wales although still slightly lower than England. Over the next fifty years, although the rate of growth in life expectancy is expected to tail off, by 2053 life expectancy in Northern Ireland is expected to have increased by a further 5.4 years for females and 6.1 years for males compared to 2003[32]. The DHSSPS aims to increase the life expectancy at birth of males and females in Northern Ireland by 3 and 2 years respectively by 2012; this represents an increase of 1.8 and 1.5 years over that projected by the Government Actuary.

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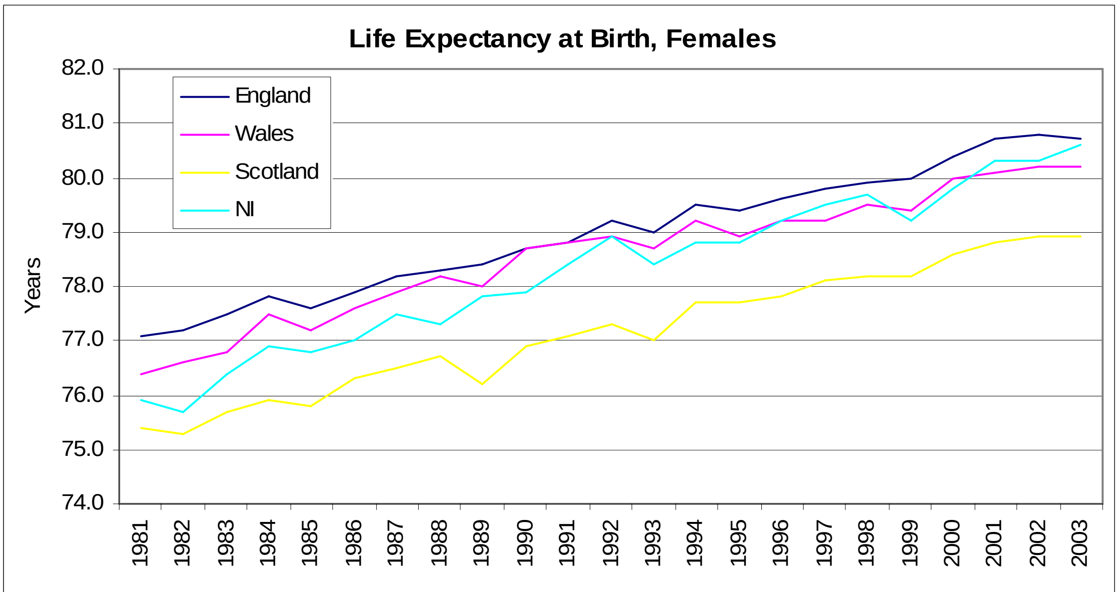
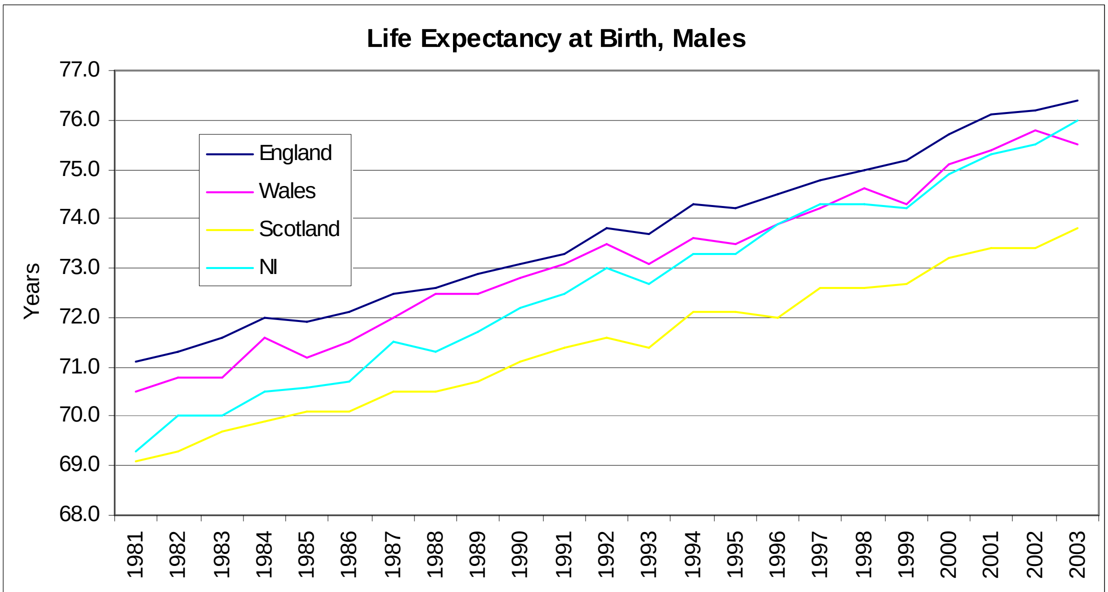
[32] Source: Government Actuary Department

Figure 3.2: Female Life expectancy (at birth) in Northern Ireland is now close to the level in England.



Source: Government Actuary Department

Figure 3.3: However, the rate of convergence with England has been greater for males.



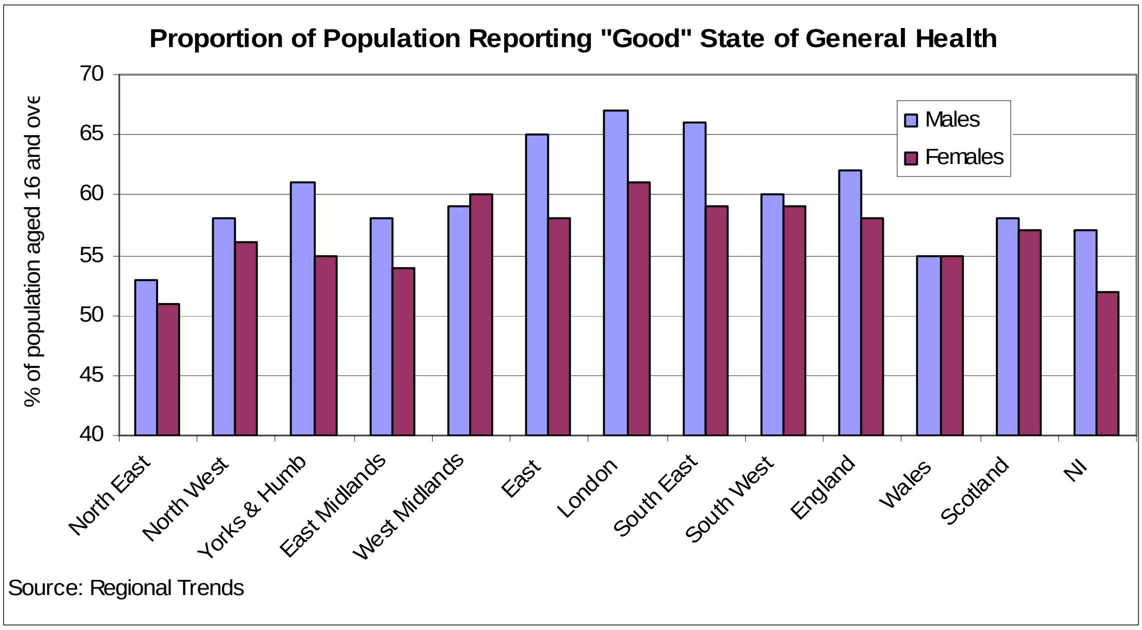
Source: Government Actuary Department

3.2.2 Self-reported health status

While mortality figures provide one perspective on the health of populations (and, with qualification, an indication of health service performance/need for investment), the vast bulk of the work and activity of health and social care services are directed at improving people's (health related) quality of life.

From this point of view, figure 3.4 - based on the General Household Survey - shows that the proportion of the population reporting themselves to be in good health is lower in Northern Ireland than most of the other regions of the UK (with the exception of the North East, and Wales with respect to males).

Figure 3.4: The proportion of population reporting "Good" state of general health in Northern Ireland is among the lowest in the UK in 2001



Source: Regional Trends

In order to expand on the information available on people's self-reported health status (and to provide data for the future funding modelling work detailed previously in section 2.3.4), the Review commissioned a special survey of 2,000 members of the public across Northern Ireland, using a generic, self-completed health status questionnaire - the EQ-5D[33].

One further reason for using this survey instrument was that the Health Survey for England also used the EQ-5D in its 2003 survey, enabling some direct comparisons to be made with the results from the Northern Ireland survey.

In the EQ-5D survey, respondents were asked the extent to which they have problems in various aspects of everyday life. Figure 3.5 shows that a higher proportion of people in Northern Ireland than England have problems with self-care and usual activities such as work and leisure activities. On the other hand, a lower proportion report problems with pain/discomfort or anxiety/depression.

It is also possible to obtain an overall measure of health status by combining these five dimensions of the EQ-5D (details of the calculations used to construct the EQ5D index are contained in Annex F)[34]. On this weighted aggregate measure, overall the population sample for Northern Ireland reported a health status some 4% *lower* than that of an equivalent population group resident in England.

This average score masks significant variations within Northern Ireland (and across England) - as figure 3.6 shows.

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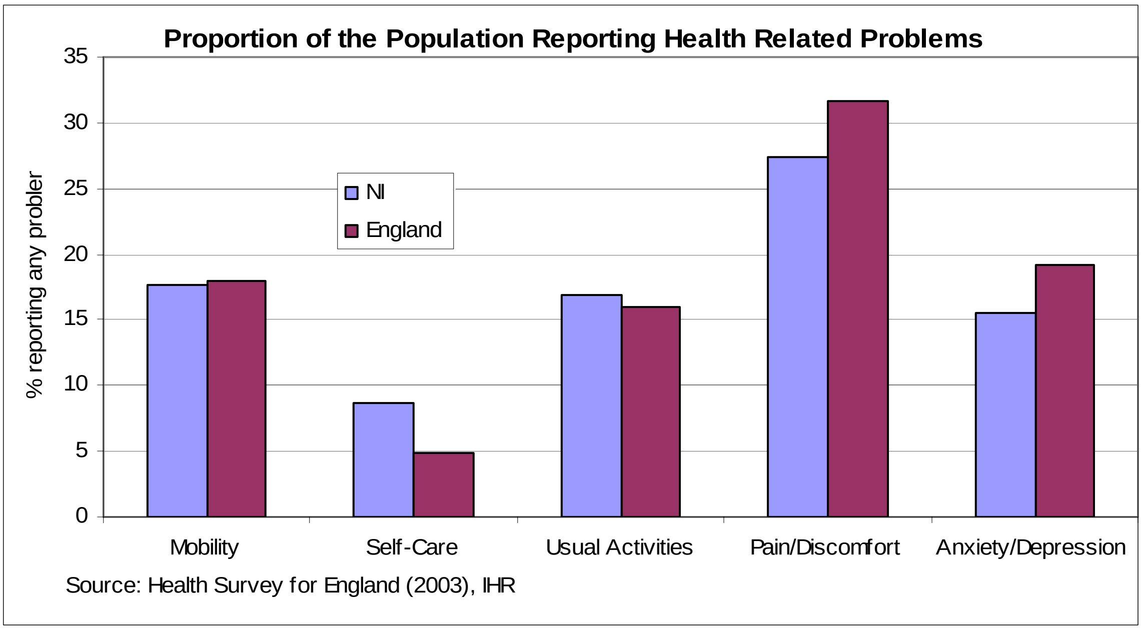
[33] The EQ-5D is a well-tested instrument often used in clinical trials as well as across populations and designed to produce a single health score. Further details of the survey are contained in Annex F

[34] When applied to subgroups of interest this index takes a value greater than 1 where health status is higher than that of an equivalent normative age/gender sample of the target comparative population. The index is lower than 1 where that health status is poorer.

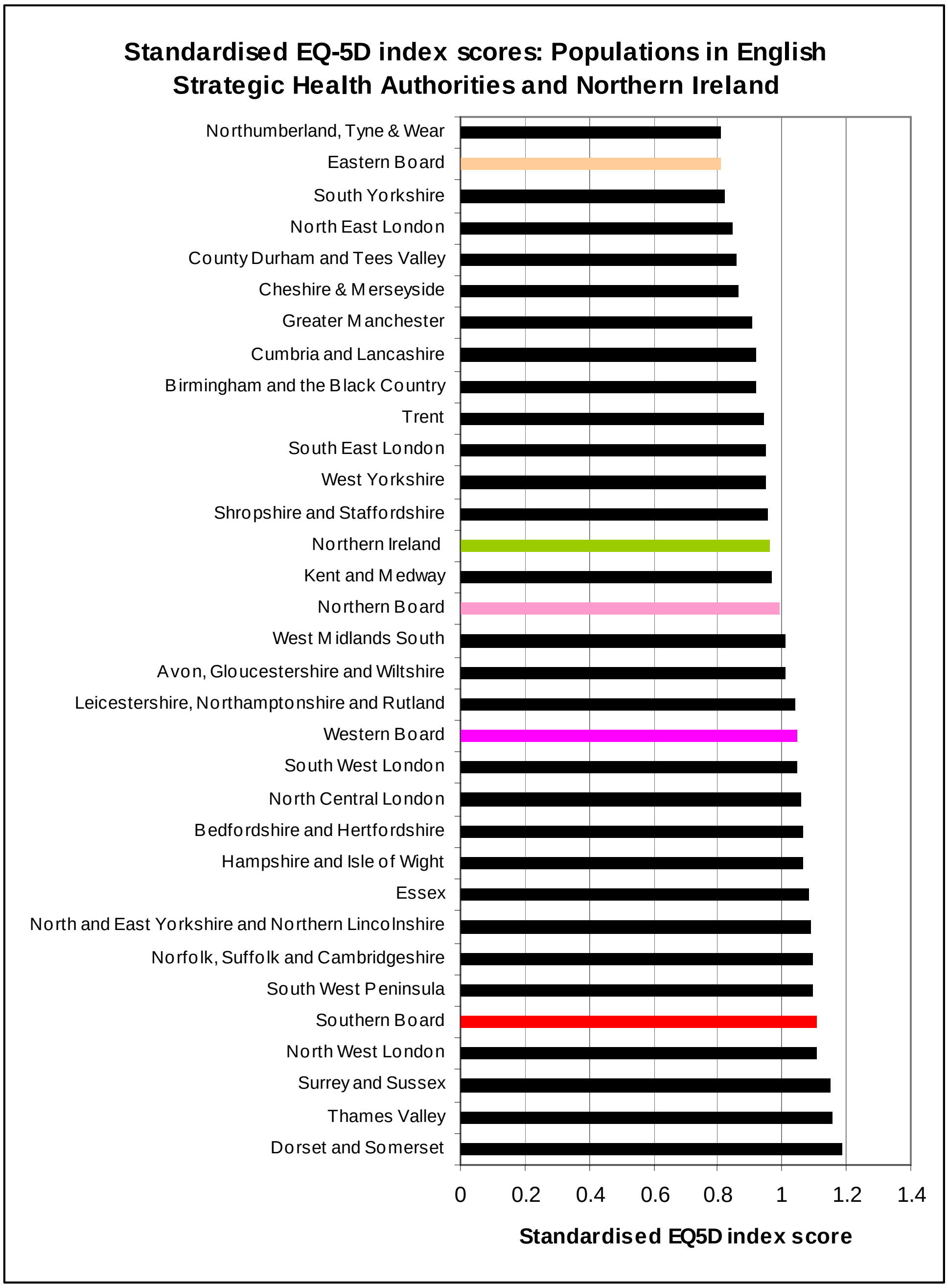
Figure 3.5: Although the proportion of the population reporting health related problems is slightly lower in Northern Ireland than England on an unweighted basis, once adjustment is made for relative social values for the five dimensions, health status in Northern Ireland is lower than in England.



Source: Health Survey for England (2003), IHR

Within Northern Ireland, for example, there were found to be a significantly higher proportion of people reporting problems with health and a lower health status score in Belfast than the rest of Northern Ireland. Whilst the Southern Health and Social Services Board would have been ranked 5th out of the 28 Strategic Health Authorities in England, the Eastern Health and Social Services Board would have been the second lowest in terms of self-reported health status as measured by a standardised EQ-5D index (see figure 3.6).

Figure 3.6: Health Status of People Living in the Eastern Health Board Area is around 16% worse than the Northern Ireland average.

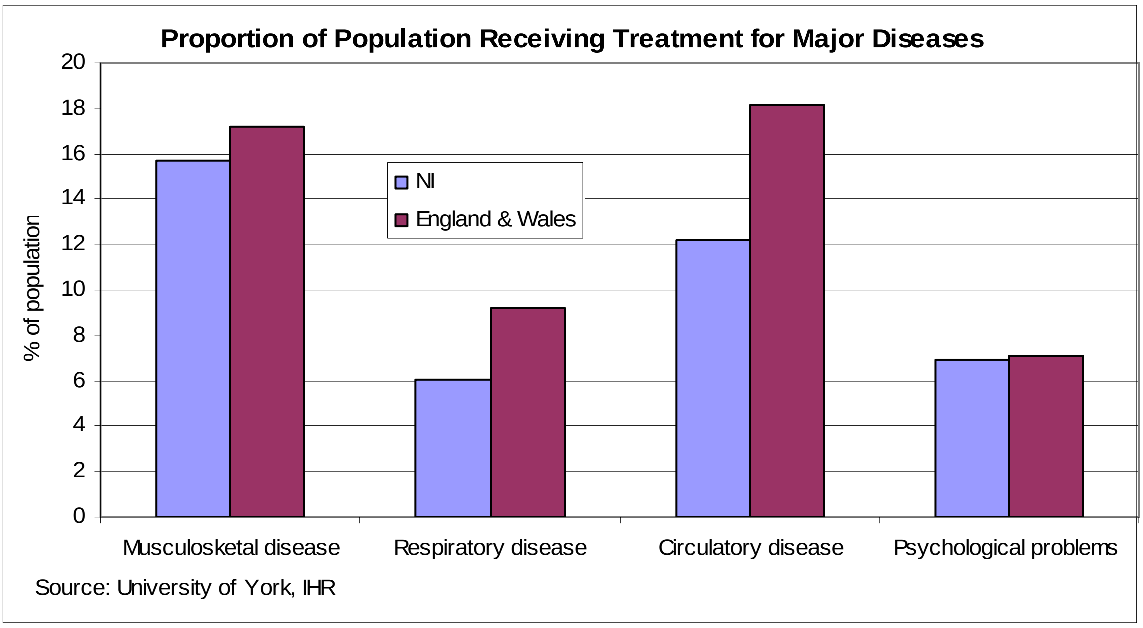


The EQ-5D survey also asked respondents to score their current state of health between 0 (representing the worst state of health) and 100 (the best possible state of health). The average score for Northern Ireland females was 76.2 compared to 76.8 for males. The overall score for people in Northern Ireland was around 3% lower than that found in previous studies for England, with the differential greater for males.

The survey also included questions relating to whether treatment was currently being received for a range of therapeutic areas. Figure 3.7 shows that there is a lower proportion of people in Northern Ireland than England & Wales currently receiving treatment. This result is somewhat surprising given that health status is worse in

Northern Ireland and is inconsistent with the data that will be presented in Section 3.3 which implies that hospital activity levels are close to the UK average in Northern Ireland.

Figure 3.7: People in Northern Ireland are less likely to be currently receiving treatment than in England & Wales for major diseases.



Source: University of York, IHR

3.2.3 Distribution of health

Although overall mortality rates are improving, there remain significant health inequalities within Northern Ireland. For example, data covering 1998 to 2002 show that mortality rates in the under 75s are 47% higher in socio-economically deprived than non-deprived wards. People in deprived areas are also more likely to be admitted to hospital - particularly as emergency admissions; admission rates for people living in deprived wards are 41% higher than in non-deprived wards, for example.

In terms of community background, 55% of those living in the fifth of wards with the worst premature mortality rates have a Catholic community background whereas 44% of the population are from this community[35].

Apart from the geographical variation in EQ-5D index scores across the four Northern Ireland health boards, the survey also recorded some characteristics of respondents - in particular, educational attainment. As figure 3.8 shows, EQ-5D index scores show a marked difference depending on educational attainment.

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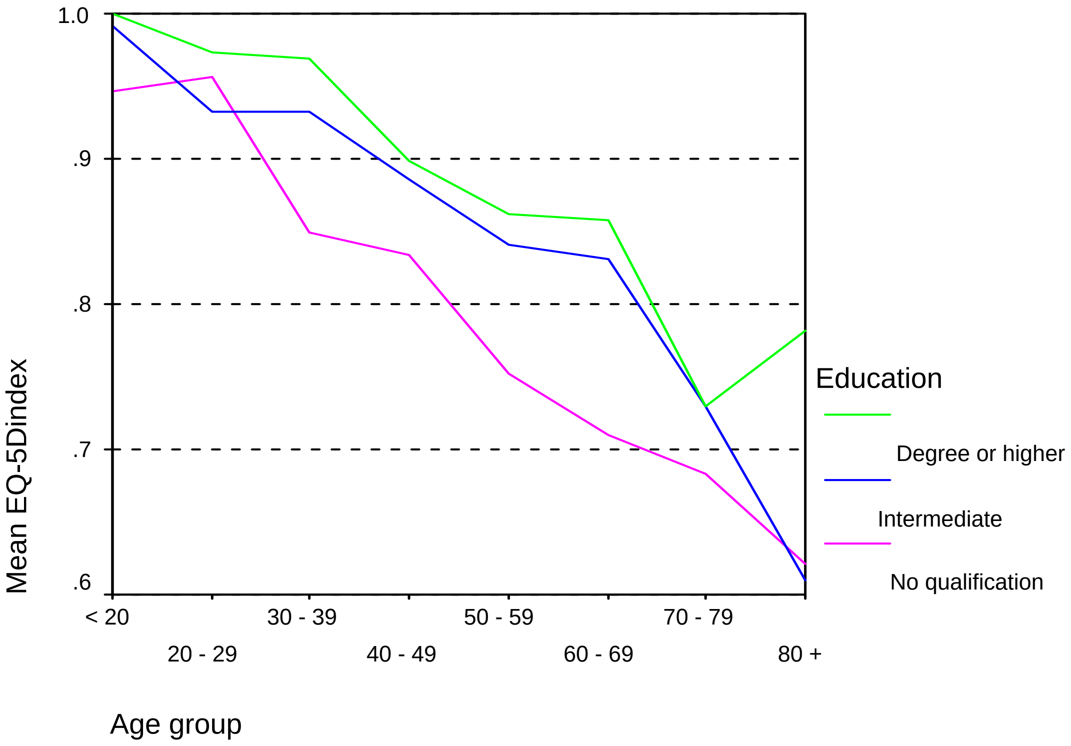
[35] Data source for this paragraph is DHSSPS report *Health and Social Care Inequalities Monitoring System: First Update Bulletin 2004*

Figure 3.8: People with higher educational attainments report better health across all age groups.



3.2.4 Lifestyles and health-seeking behaviour

As we note above, the determinants of a population's health are many and varied and while the level and distribution of health and social care services plays an important part in explaining changes in health, lifestyle factors - particularly for some diseases, for example, lung cancer - are also an important contributor to the general health well being of the population.

Table 3.1 sets out the main comparisons in terms of key lifestyle behaviours - diet, smoking, drinking, exercise and cancer screening. It can be seen that Northern Ireland has higher levels of fat intake and excessive drinking than England & Wales, whilst physical activity is below the rest of the UK. Although the proportion of people who smoke - around a quarter of the population - is similar to other parts of the UK, Northern Ireland has a higher percentage of heavy smokers. In terms of prevention, although the proportion of women screened for breast cancer is higher than in England & Wales.

Heavier drinking and smoking coupled with a high fat diet and a sedentary lifestyle add up to poorer health outcomes - regardless of the best efforts of the health services. But unhealthy lifestyles not only affect health outcomes but also place significant resource pressures on the health and social care system as they address the health consequences and with a consequential impact on the level of service provision (as shown in the UK Wanless Report[36]).

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[36] The Final Report of the UK Wanless Review, Securing our Future Health: Taking a Long-Term View, projects under the solid progress scenario (which incorporates inter alia the meeting of public

Table 3.1: Prevalence of healthy lifestyle choices for UK countries

	England	Scotland	Wales	NI
Fat intake per day (grams)[1]	73	71	73	76
% of people who smoke[2]	26	28	27	26
Excessive Drinking (Males)[3]	21	29	23	27
Exercise (%)[4]	11.4	10.4	12.8	7.1
Cervical Cancer Screening (%)[5]	81.6	86.5	80.0	72.2
Breast Cancer Screening[6]	69.8	75.0	66.6	72.6

Source: National Statistics, NISRA

Notes:

1. 1999/2000 data
2. 2002/03 data for persons aged 16 and over
3. 2000/01 data for persons aged 16 and over relating to more than 8 units of alcohol in past week
4. 2000 data based on minutes per day spent on physical activity as a % of sedentary activity
5. March 2002 data as % of all aged 25-64
6. March 2002 data as % of all aged 50-64

Recommendation 7: Routine collection of self-assessed health status data at population level would yield useful comparative data on population health status. In addition, the potential for routine collection of patient related outcome measures in health care services should be explored.

Recommendation 8: On the basis of current lifestyle data, the funding recommendations based on the Wanless 'fully engaged' scenario (investigated in more detail in a subsequent report[37]) imply considerable effort will be needed to engage the Northern Ireland population through expanded public health services and other means.

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health targets) a 12.5% lower need for expenditure by 2022/23 than under the slow uptake scenario where no change in public health behaviour is assumed.

[37] In April 2003, the Prime Minister, the Chancellor and the Secretary of State for Health asked Derek Wanless to provide an update of the challenges in implementing the fully engaged scenario set out in his report on long-term health trends. Derek Wanless' final report "Securing Good Health for the Whole Population" was published on 25th February 2004.

3.3 Utilisation and activity[38]

While the population's health is a central factor explaining the level of use of health services, it is important to bear in mind that the use of services is a reflection not only of the need for care, but also the availability of services; demand (need) is not always independent of supply. In this section we examine secondary care utilisation and activity (including the independent sector). Subsequent sections examine family health services and personal social services and contain a wider ranging discussion of funding and organisation of these sectors.

3.3.1 Hospital activity

Figure 3.9 sets out an aggregate measure of secondary care activity in terms of inpatient, day case, out-patient and A&E attendances per head of population, weighted and summed on the basis of unit costs[39]. It can be seen that on this measure, Northern Ireland has a very similar level of aggregate hospital activity to England and marginally lower than the UK as a whole (see Box 3.1 regarding differences between published activity statistics and those used in this Review).

Box 3.1: Hospital activity data

Publicly available information on hospital activity has, from 1998/99, included data on renal dialysis treatments. These number around 33,000 deaths and discharges in 2003/04 - equivalent to around 10% of all inpatient cases across Northern Ireland. While these cases have been included in published statistics for hospital activity in Northern Ireland, here we exclude them as they distort comparisons (and time trends) as such cases are not included in the inpatient activity statistics for Great Britain. This exclusion has a significant impact on activity trends and productivity measures noted later in this review.

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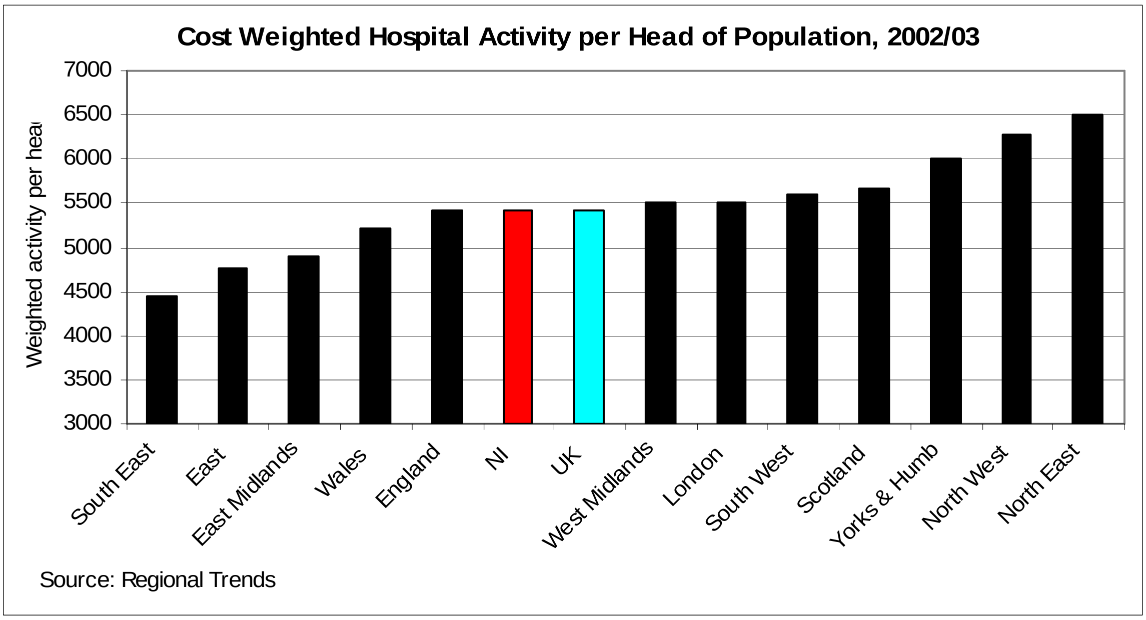
[38] In this section the terms utilisation and activity are used interchangeably.

[39] This is similar to the cost weighted activity index (CWAI) used in aggregate measures of efficiency and enables the aggregation of activities measured in different units - attendances, hospital stays etc.

Figure 3.9: Aggregate cost-weighted hospital activity per head of population in Northern Ireland is slightly below the UK average, 2002/03.



Source: Regional Trends

However, this aggregate measure of hospital activity masks an important difference with England. In particular, figure 3.10 shows that the level of accident and emergency attendances per head of population in Northern Ireland is 31% higher than in England[40]. Why this should be so (and indeed, why this has remained the case for many years) is not clear. Higher levels of provision and deprivation, a culture of using A&E in preference to general practice and problems with out of hours GP services have been offered as explanations, but to the knowledge of this Review there have been no in-depth studies or analysis to verify these explanations or explore the appropriateness of this level of A&E utilisation.

> **Recommendation 9: Further investigation is required of very high A&E use to explore reasons and find ways for reducing likely inappropriate use**

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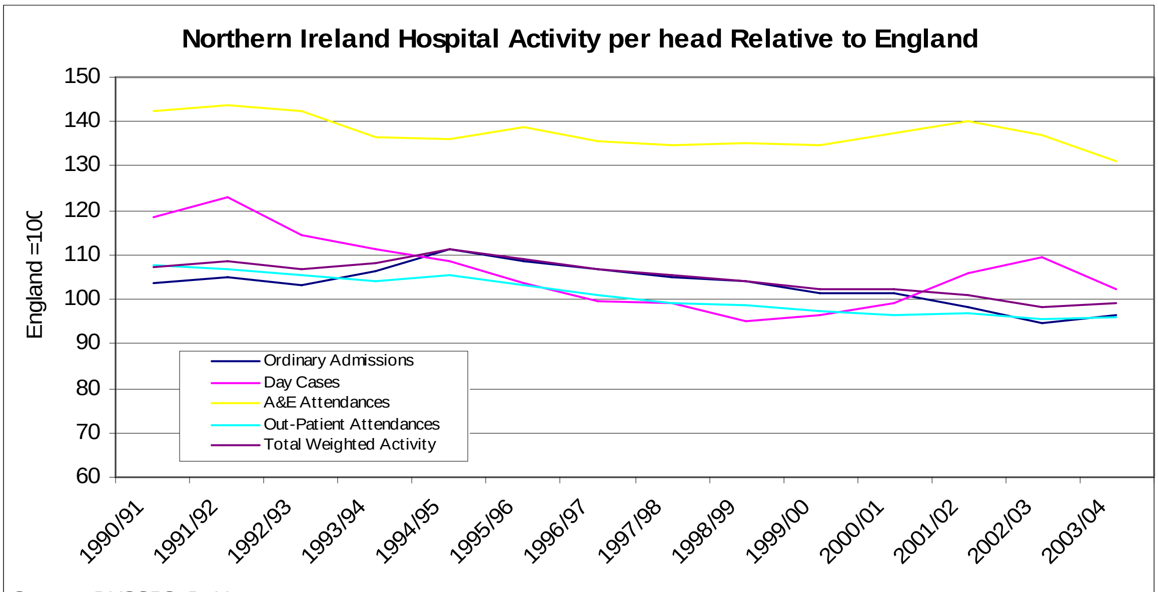
[40] Provisional figures for 2004/05 indicate that the gap between Northern Ireland and England has fallen to 28% although A&E attendances in Northern Ireland still rose by 1.7% over the year.

Figure 3.10: The number of A&E attendances per head of population is 31% higher in Northern Ireland than England whilst there are 4% fewer out-patient attendances.



Source: DHSSPS, DoH

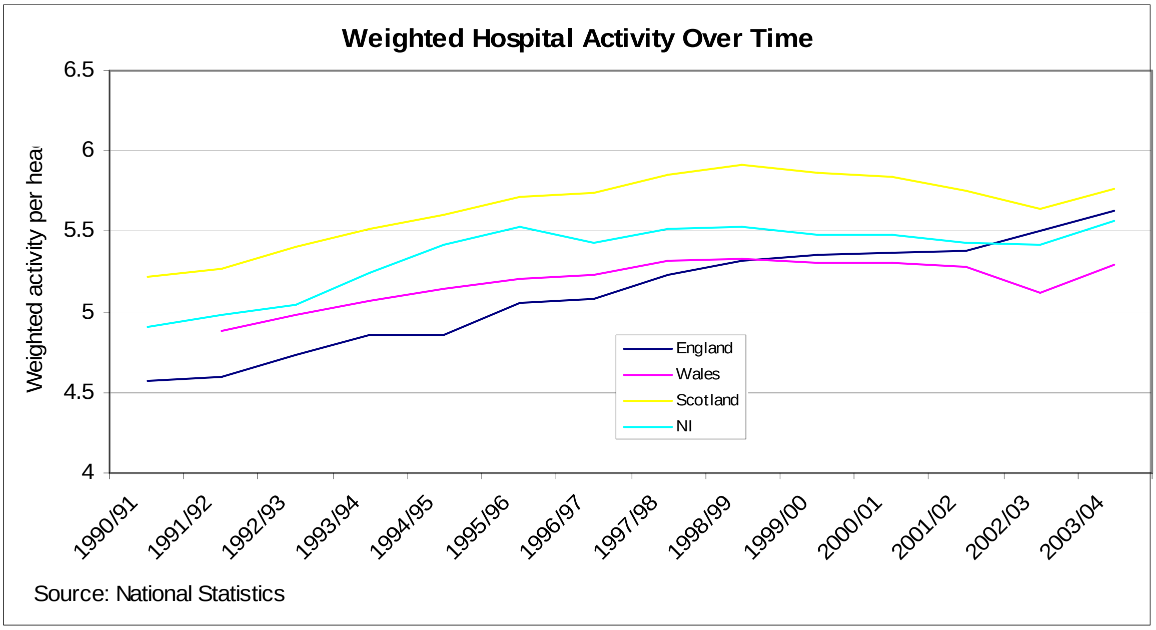
As for change in hospital activity over time, Table 3.2 shows that over the past decade there has been significant growth across the UK, with the rate of growth being highest in day cases and lowest in A&E. Unadjusted hospital activity in Northern Ireland has increased at a faster rate than in Scotland, but more slowly than England and Wales. However, once the higher weighting given to inpatient activity is incorporated, then Northern Ireland has had the second fastest growth in hospital activity

Table 3.2: Annual average growth in hospital activity, 1990/91-2003/04

	England	Scotland	Wales	NI
In-Patients	1.3	0.5	0.5	0.9
Day Cases	9.9	5.1	8.8	8.9
A&E	0.8	0.4	0.9	0.3
Out-Patients	1.7	0.1	1.6	1.0
Weighted total	1.9	0.7	0.8	1.5

Growth in utilisation and activity since 1990 has not been even, however. As figure 3.11 shows, most of the growth in activity occurred in the early part of the 1990's with slower growth subsequently. Since 1990/91, activity levels per head of population in Northern Ireland, Scotland and Wales have moved broadly in tandem, with little or no growth since 1997/98. However, levels of activity in England have been on a continual increase since 1996/7.

Figure 3.11: Scotland, Wales and Northern Ireland have not experienced significant growth in weighted hospital activity per head of population since 1997/98.



Source: National Statistics

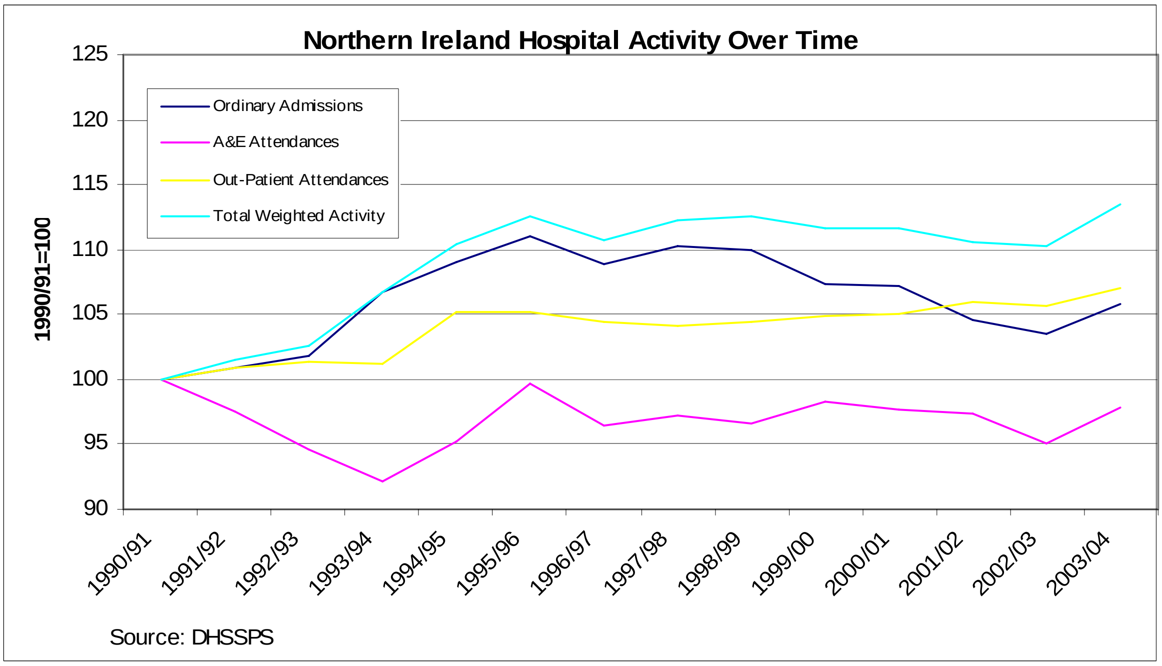
The trends in activity for Scotland, Wales and Northern Ireland show, as figure 3.11 indicates, a distinct change more recently, with sharp increases in 2003/4.

This increase in 2003/4 is also noticeable in trends for Northern Ireland in ordinary, and day case admissions and outpatient attendances (see figure 3.12). Figure 3.12 also shows that whilst the total number of ordinary admissions is now close to the level it was a decade ago, this has followed a nearly continuous decline since 1995/6.

Disaggregating ordinary activity further, shows, in figure 3.13, that the rise in ordinary activity in 2003/4 was wholly attributable to an increase in the number of emergency admissions to hospital. Importantly, the number of *elective* admissions - which include admissions from waiting lists - has been steadily falling since the mid 1990s and is now nearly a quarter lower than it was in 1994/5. This trend in elective admissions provides part of the explanation for the growth in waiting lists and times examined in more detail in section 3.6.

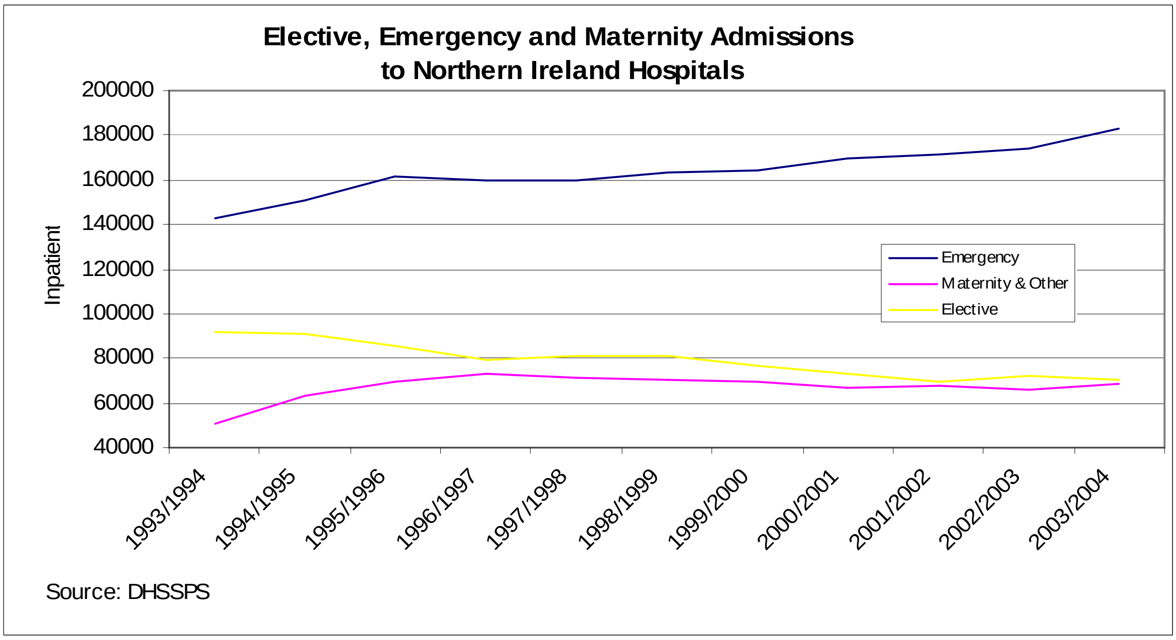
> **Recommendation 10: Detailed analysis is needed into hospital activity trends as part of a broader analysis of the dynamics of waiting times and lists.**

Figure 3.12; There was a significant increase in all forms of hospital activity in Northern Ireland in 2003/04



Source: DHSSPS

Figure 3.13: The number of emergency inpatient admissions has increased by 23% since 1993/94 whilst the number of elective admissions has fallen by 24%.



Source: DHSSPS

3.3.2 Private sector health & social care[41]

Despite recent growth, the private sector contributes only a small proportion of health care activity in the United Kingdom and an even smaller share for Northern Ireland. The private sector has the potential to benefit the health care system through raising

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[41] Although the main focus here is on hospital activity, the private sector also has a significant role to play in the provision of nursing homes places as well as community/social care packages.

capacity, and, given a competitive economic environment, increasing pressure on public sector providers to improve performance by providing an alternative to the public sector[42]. However, private healthcare providers can also have a detrimental impact by exacerbating staff shortages in the public sector as well as creating financial uncertainty.

Prior to 2000, the Government's policy in England was to oppose any expansion of the use of the private sector to provide clinical services to NHS patients. However, with the publication of the NHS Plan and the identification of short term NHS capacity constraints as a hurdle in tackling waiting times targets set by the Plan, the purchase of private sector capacity by the NHS on behalf of NHS patients was seen as a way forward. By the end of 2005, private providers will carry out 4 per cent of publicly financed elective treatments in England, rising to 15% under Government plans[43]. There are no immediate plans for the Northern Ireland health & social care sector to follow such an approach, despite having longer waiting lists. Whilst acknowledging that in the coming years an increased number of patients will be treated in the private sector, the DHSSPS Regional Strategy for 2005-2025[44] raises concern regarding competition for staff.

The distinction between the public and private sector can be defined in terms of payment and provision. In terms of payment, 10% of all households in Northern Ireland have Private Medical Insurance whilst in Great Britain the range is from 8% in the North-East of England to 26% in the South-East, with a UK average of 17%[45]. In terms of provision, there are currently only two private hospitals in Northern Ireland with a total of 84 beds. This equates to approximately 0.05 beds per 1,000 population compared to 0.18 for the UK as a whole and 0.11 in Wales.

Private activity also takes place in public sector facilities. And in addition, Health Boards purchase treatments on behalf of the NHS from private health care providers not only in Northern Ireland but Great Britain and the Republic of Ireland as well.

Private activity in Northern Ireland's HPSS hospitals accounted for 1.4% of all finished consultant episodes in 2003/04, and 0.6% of out-patient attendances. Over half of all these outpatient attendances were for two specialties, gynaecology and cardiology.

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[42] But this depends on how competitive the private sector is. For example, the NAO Wales report into NHS waiting times found that the average private sector costs for certain procedures was higher in the NHS whilst private treatment centres in England are being paid at rates above the national average.

[43] Source: The Economist 9-15 April 2005

[44] DHSSPS: A Healthier Future, A Twenty Year Vision for Health and Well-being in Northern Ireland 2005 – 2025

[45] Source: Family Resources Survey 2002/03

Table 3.3: Northern Ireland NHS hospitals treat a higher proportion of patients privately than in England or Wales.[1]

	In-Patients	Day Cases	Out-Patients
Northern Ireland	0.7	2.9	0.6
Wales	0.3	1.1	0.3
England	0.9		0.5

Source: DHSSPS, NAW, DoH
NI data is for 2003/04 whilst England and Wales are for 2002/03

Whilst this is a relatively small proportion, it is higher than in England and Wales (see table 3.3). However, the level of NHS income derived from private patients per head of population in Northern Ireland is less than half that for the UK as a whole[46]. This would suggest that either private activity in Northern Ireland hospitals is less costly than in Great Britain or that the HPSS is not charging the full economic cost for the use of facilities. Over the past five years, whilst the number of private day cases in Northern Ireland hospitals has fallen by 3%, the number of in-patients has increased by 13% and out-patients by 42%.

In 2003/04, Health Boards spent £10m on the treatment of 3,000 patients transferred to private health care providers - mainly as part of initiatives to reduce waiting lists[47]. This is equivalent to around 4.4% of the elective inpatient finished consultant episodes carried out in the HPSS in 2003/04. Whilst the number of patients treated under these initiatives has increased by 64% since 2001/02, expenditure has risen by 125%. The cost per treatment appears to be higher under these waiting list initiative than the unit cost for elective procedures in the HPSS. There is also some variation in cost between Boards[48]. Although this may simply reflect differences in case mix, in light of the concerns raised by the Welsh Audit Office[49] with respect to the use of private provision by the NHS in Wales it is important that this spending is audited for value for money.

Whilst the private sector remains a relatively insignificant provider in terms of the entirety of health service provision in Northern Ireland, at the margins it can make an important contribution to certain areas, in particular in tackling waiting lists[50]. However, while purchasing NHS care from the private sector can add a useful element of flexibility, value for money remains a stumbling block to any long term use of this capacity.

The impact on overall effectiveness of private activity in HPSS hospitals depends on the extent to which it represents additional capacity as opposed to an inequitable skewing of resources towards those who are willing and able to pay. In addition, whilst the treatment of HPSS patients in private health care facilities may represent a

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[46] Laing's Healthcare Market Review estimate NHS income from private patients to be £408m in the UK in 2003/04 whilst HPSS income generated from private patients in NI for 2003 was £585k (Source: DHSSPS).

[47] Waiting list initiatives accounted for 98.2% but only 78.2% of spend as the remaining treatments were under Extra Contract Referrals where patients are referred to private healthcare providers as the specialist treatment they require is not available locally in a NHS hospital.

[48] In 2002/03 the cost per treatment under private health care Waiting List Initiatives was £2,600 (range £1,739-3,982 between Boards) whilst the unit cost per elective FCE was approximately £1,800.

[49] : NHS Waiting Times in Wales Volume 2 Tackling the Problem, National Audit Office Wales

[50] There were more people treated under private health care Waiting List Initiatives in 2003/04 (2,908) than there were Excess Inpatient Waiters in December 2004 (2,381)

pragmatic approach to supply constraints, it is important, as noted earlier, that value for money is achieved.

The level of private sector provision depends on a range of factors, including income levels, service provision in the public sector and Government policy. The current relationship with the private sector appears to have grown more out of necessity than design. It is important that there is clear direction from DHSSPS as to the role of private health care providers in the broader Northern Ireland health & social care sector so that their capacity and capabilities can, where appropriate, bring most benefit to patients.

> **Recommendation 11: DHSSPS to develop a more coherent strategy towards partnership with private sector**

3.3.3 Cross Border Co-operation

The Republic of Ireland (RoI) has a different system of health and social care from that in Northern Ireland, with service users in the RoI having to pay for treatment provided free north of the border. For example, there are charges for GP appointments and hospital attendances - although around a third of the population are entitled to free health care and there are limits on the cost of services provided by the state. In addition, a large proportion of the population in the Republic of Ireland are privately insured (in which some Northern Ireland Hospitals participate[51]). Eligibility for care in both jurisdictions depends mainly on residency, although there are a number of exceptions under EU regulations, such a cross border workers.

In 2001/2, there were 2,430 RoI residents treated in Northern Ireland hospitals - under 1% of the total hospital activity in Northern Ireland. In comparison, 902 Northern Ireland residents were treated in RoI hospitals in 2002, equivalent to 0.17% of admissions. However, around 90% of the activity involving RoI residents in Northern Ireland hospitals is paid for either privately or through contracts between health boards. In addition, emergency treatment is covered by a reciprocal arrangement between RoI and Northern Ireland. Whilst Northern Ireland trusts do receive payment for non-emergency activity from the Republic of Ireland there is a question, as with private activity in general, as to whether the full economic cost is being charged.

The main cross border health and social care initiative is ‘Co-operation and Working Together’ (CAWT), which was established in 1992 by the four health boards located along the border between Northern Ireland and the Republic of Ireland, to facilitate cross border co-operation.

Through CAWT, the Southern and Western Health and Social Services Boards in Northern Ireland and the North Eastern and North Western Health Boards in the Republic of Ireland agreed to co-operate in order to improve the health and social well being of their respective populations. Recent projects have been taken forward in the area of emergency planning and pre-hospital emergency care.

However, the projects to date appear to have been rather small scale, not involving major issues such as the location of hospitals specifically to provide services on both

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[51] Royal Victoria Hospitals, Altnagelvin and Daisy Hill.

sides of the border. Although this issue was considered by the Acute Hospitals Review Group in terms of the provision of hospital services in the south-west of Northern Ireland, there appears to have been very little in the form of joint planning of hospital services.

Given the relatively small scale of the health & social care system in Northern Ireland it is entirely sensible that services are provided on a cross-border basis where appropriate. This would ensure that as broad a range of services can be provided as close to patients as possible. Whilst there is reluctance on the part of some patients in border areas to access services in the Republic of Ireland, it does not make economic sense to, for example, have two small hospitals on either side of the border when one larger hospital could provide a better service to both communities.

3.4 Family Health Services

Primary care covers a wide range of services provided by a number of different health and social care professionals. It is an integral part of the whole system of care and is often the first point of contact for people who need help, support and advice from the health and social services.

There has been increased emphasis in recent years for primary care to take on more activity and direct fewer patients to other more expensive parts of the health & social care system. However, there is concern that that the resources required to facilitate this move have not been transferred. Concurrently, some of the clinical roles and responsibilities carried out by GPs are to be transferred to practice nurses, community pharmacists and other allied health professionals as part of a multi-disciplinary team, with more people being treated at home.

Family health services comprise: General medical, pharmaceutical, dental and ophthalmic services. The majority of expenditure is spent on the first two service areas; dental and ophthalmic services have not been covered as part of this Review. However it should be noted that the number of dentists and optometrists per head of population in Northern Ireland is the highest of the UK countries.

As in the rest of the UK, general medical services in Northern Ireland were delivered under the terms of the 1990 GMS contract. This allowed GP practices to operate a system of fundholding. While not all practices in Northern Ireland operated under fundholding, the majority did.

Under fundholding, individual GP practices were allocated a budget each year. Each practice controlled how this money was spent and what services were provided to their patients. Hospital costs for patients and practice staff costs were also met by each individual practice. Fundholders were also allowed to retain any savings made by the practice for reinvestment in future years.

There was a perception that fundholding contributed to an inequitable service. Following the abolition of fundholding in England and Wales and the establishment of Primary Care Groups (which evolved into Primary Care Trusts) a decision was taken to abolish fundholding in Northern Ireland. Fundholding was abolished in March 2002 and resulted in all GP practices being funded directly by Boards. Under the new system all hospital costs were also met by Boards as were practice staff costs and rents and rates of GP practices.

Local Health and Social Care Groups (LHSCGs) were established on the abolition of GP Fundholding. There are currently 15 LHSCGs based in local Trust areas and working across all areas of health and social care to address gaps in local service provision and to develop primary care services[52]. The Groups are required to develop links with their communities, all primary care stakeholders in their areas and other relevant agencies. It was envisaged that the LHSCGs would progressively receive larger budgets devolved from the health boards to allow them to develop a greater commissioning role[53].

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[52] However, under the recommendations from the Review of Public Administration the number of LHSCGs will need to be reassessed.

[53] *Building the Way Forward in Primary Care*, DHSSPS Consultation Paper, December 2000.

However, amongst the 60% of GPs previously operating as fundholders there was significant resistance to the abolition of fundholding and a reluctance to become involved in the LHSCGs. There were two contrary views expressed by the groups and individuals we met as part of the consultation process on this matter. One was that the lack of GP involvement meant that LHSCGs were unable to develop and take on greater responsibility for the commissioning of services. The other was that the lack of responsibility and funding meant that LHSCGs were a step back for GPs, and that as a consequence there would be little point in becoming involved. The issue of GPs' involvement in allocation/purchasing decisions is returned to in Section 4 as part of suggestions for improving the performance management system.

A new national GP contract was implemented in April 2004. Its aims were to reward practices for higher quality care, improve GPs working lives and ensure patients benefit from a wider range of services in the community. In addition the news GMS contract is expected to lead to a fairer system of funding as well as the overhaul and modernisation of ICT infrastructure. The contract was negotiated and implemented on a UK wide basis. he new contract resulted in a 25% increase in spend on primary care between 2003-04 and 2004-05 when the new contract was implemented. In the first year this increased investment has resulted in practices achieving a significant proportion of the quality targets which had been set.

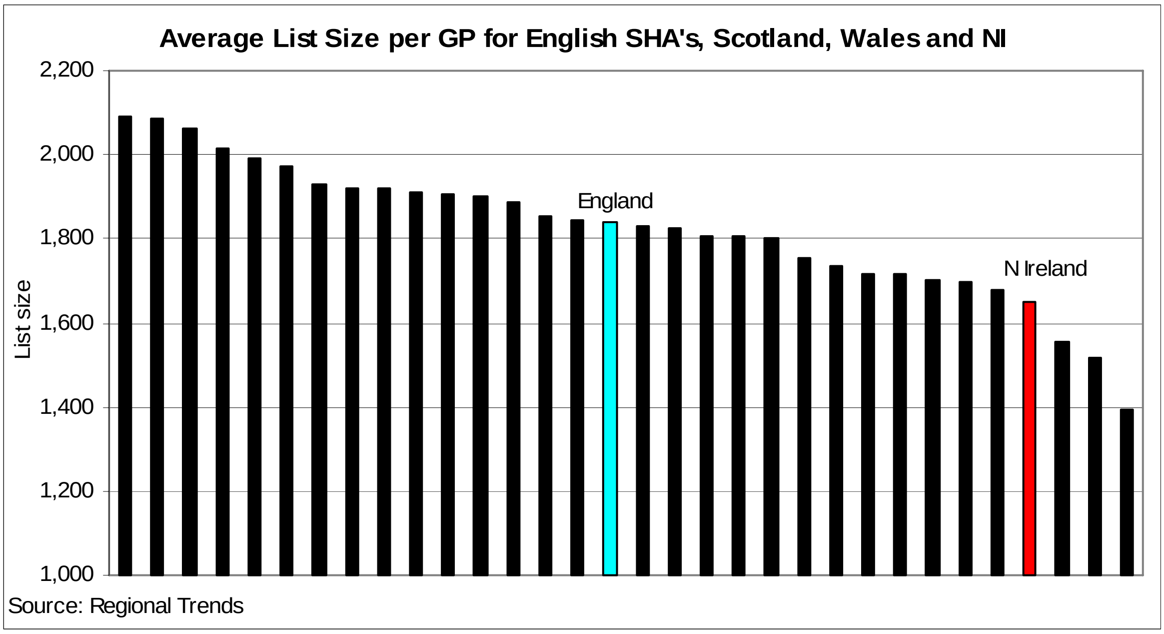
The new contract also meant that GPs could opt out of the responsibility for securing the provision of out of hours services and this would then transfer to Boards. Most, if not all GPs opted out of this responsibility and Boards have been responsible for re-provision with effect from 1 January 2005. The cost of providing this service was estimated at £21m. GPs who opted out of this responsibility were required to pay back a proportion of their funding designed to provide services to their patients and this amounted to some £5.5m in 2004-05. There is a question here of why the fall in income was not more in line with the cost of providing the transferred services.

The new GMS contract delivers financial rewards for high quality care. The maximum quality points that can be achieved under the contract is 1050. In the original estimates for funding the contract, assumptions were made that approximately 75% of these points might be achieved but in practice GPs in Northern Ireland have achieved some 90%-95% of these targets which has resulted in an additional pressure of some £9m on the existing GMS contract envelope.

An important issue is that it is not clear that the better than expected performance in meeting targets reflects an improvement in quality of service or that the targets set were insufficiently challenging. If the former, then the ability of GPs to significantly improve quality outcomes in such a short period of time raises serious issues regarding past performance.   DHSSPS have indicated that an objective of the new contract was to ensure that GPs are now remunerated for services they had previously provided in addition to their core terms of service but were not paid for. In other words, there was a 'deadweight' cost implicit in the new contract. However, it is unclear whether this phenomenon, common to many NHS employees, was significantly greater in respect of GPs.

There are currently around 1,100 GP's working in 366 practices in Northern Ireland. The number of GP's has increased by over a fifth in the past twenty years with the result that list sizes have fallen by over a tenth. Figure 3.14 below shows that GP list sizes in Northern Ireland are lower than the rest of the UK, with the exception of Scotland and the South-West of England.

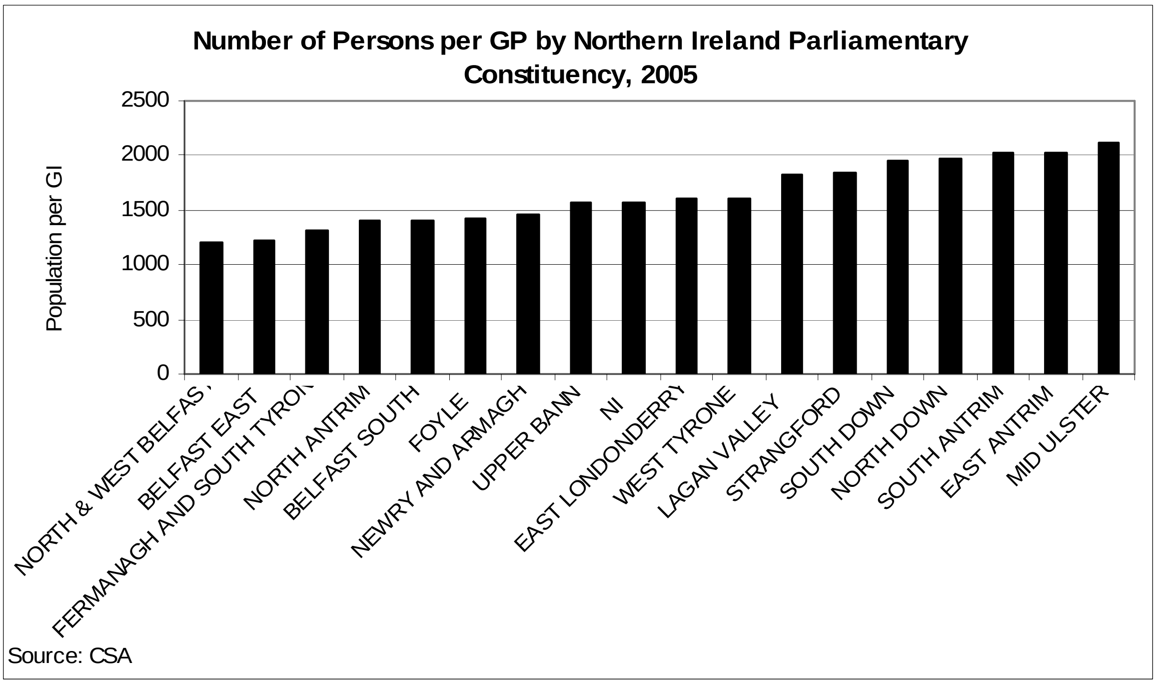
Figure 3.14: GP List Sizes in Northern Ireland are 10% lower than in England, 2002



Source: Regional Trends

And figure 3.15 shows that there are significant variations within Northern Ireland in terms of the resident population per GP, with North & West Belfast having around 1,210 persons per GP compared to 2,110 for Mid Ulster.

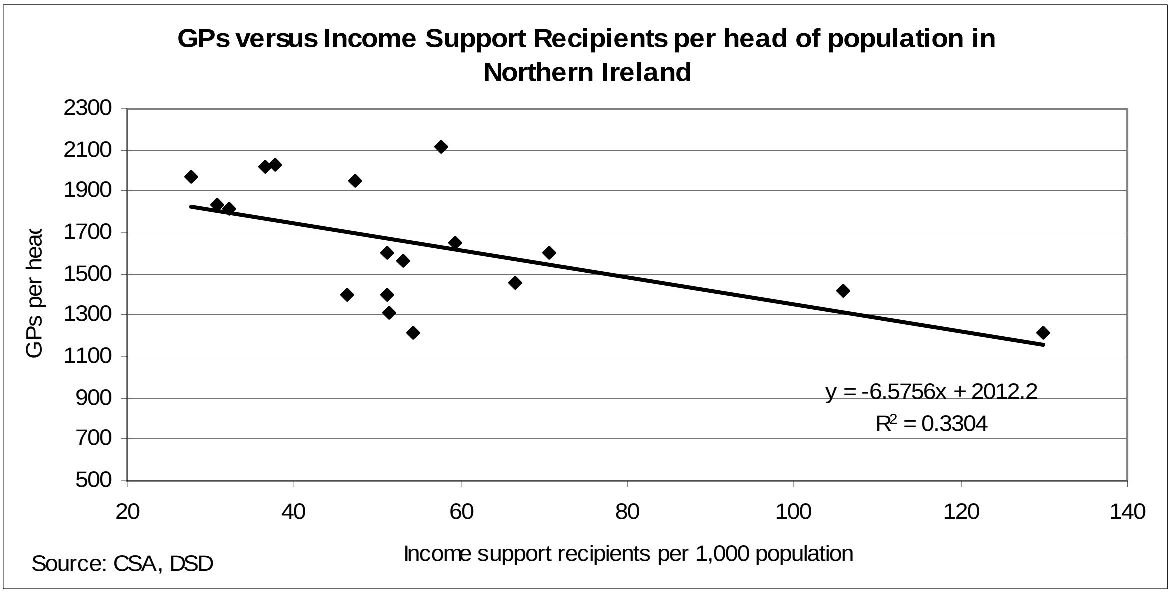
Figure 3.15: The number of persons per GP is 74% higher in Mid Ulster than North & West Belfast



Source: CSA

However, this appears to reflect the higher numbers of income support recipients - as shown in figure 3.16. The number of recipients is taken as an indicator of deprivation, and as those in deprived areas tend to have higher rates of illness it is assumed that they would require more attention per patient from GPs, necessitating smaller GP list sizes.

Figure 3.16: There is a negative correlation between Income Support recipients and GPs list sizes in Northern Ireland Parliamentary Constituencies .



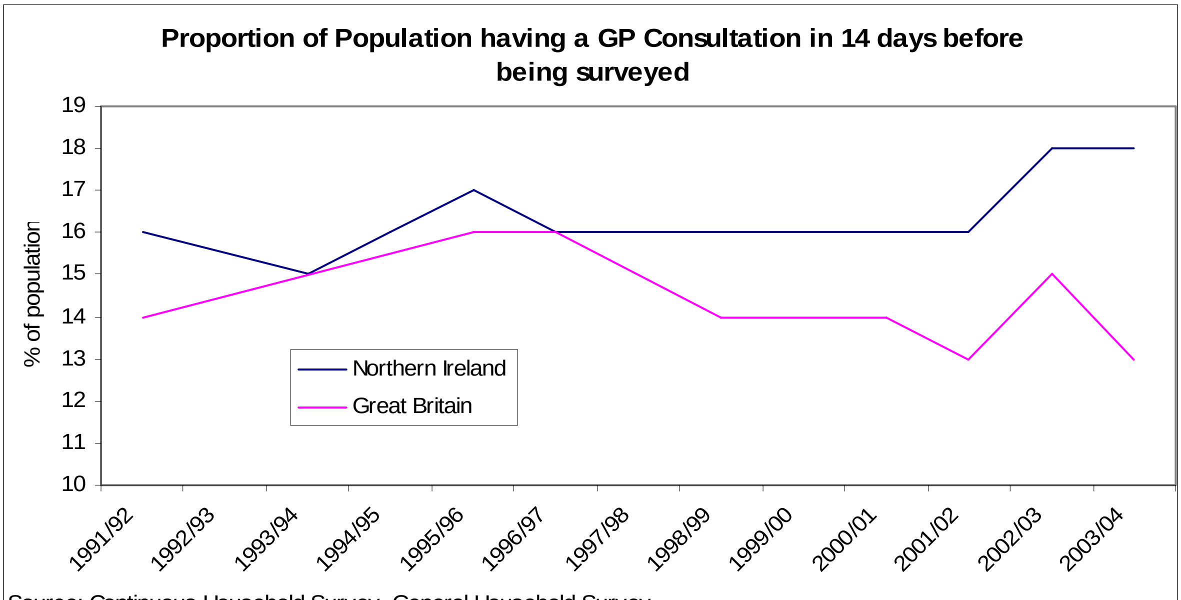
Source: CSA, DSD

In terms of work load, whilst figure 3.14 shows that GP list sizes are smaller in Northern Ireland than in most other areas of the UK, the number of GP consultations per head of population is higher.

Figure 3.17 shows that 18% of the Northern Ireland population had a GP consultation in the previous 14 days compared to 13% in Great Britain. In addition, whilst there appears to be a general downward trend in GP consultations in Great Britain since the mid 1990’s, this has not been replicated in Northern Ireland. This raises the question of whether the higher rate of GP attendance reflects a greater level of need, or that alternative forms of treatment might be more appropriate.

A recent survey of GPs carried out by the Central Services Agency found that 48% of respondents reported that their morale as a GP was low, whilst 93% felt that too much is being asked of general practice. And nearly half stated that they would sacrifice some income in order to have less work - of concern given the increasing roles that are being expected of GP practices, and in particular the implications of the new GMS contract (with which, only a fifth were satisfied). Almost two-thirds felt that patients receive better care in general practice than five years ago. Surprisingly, only 58% of GPs agreed that a GP in a deprived area has to cope with more pressures and stress than a GP in a less deprived area.

Figure 3.17: The Proportion of the Population having a GP Consultation in the previous 14 days is nearly 40% higher in Northern Ireland than GB



Source: Continuous Household Survey, General Household Survey

3.4.1 Prescriptions

One of the main issues of concern with the provisions of health & social care services in Northern Ireland has been the relatively high level of GP prescribing[54]. In response, DHSSPS have introduced a variety of initiatives including the Prescribing Incentive Scheme which encourages GPs to make more effective and efficient use of prescribing resources by rewarding practices financially for achieving savings – practices were allowed to keep up to 60% of savings achieved in 2004/05.

GP prescribing is routinely monitored by prescribing advisers in each of the Health and Social Services Boards. Their role is to engage with GPs to encourage safe, rational and cost effective prescribing. The main method of communication with GPs and practice staff is by practice visits aimed at:

- Agreeing actions related to prescribing
- Discussion of evidence of change in prescribing
- Responding to queries on prescribing

A key objective of prescribing advisers is to increase the level and appropriateness of generic prescribing by for example compiling a list of generic switches and agreeing these with practices.

The COMPASS system provides on a quarterly and annual basis a range of prescribing reports and therapeutic notes to all GPs, Local Health and Social Care Groups, Boards' prescribing advisers and the Department. Each report provides an analysis of the prescribing at individual practice level, suggesting alternative approaches that might improve effectiveness, safety and patient care and showing

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[54] However it may be that for example the quicker uptake of new drugs in Northern Ireland, whilst increasing the drugs bill, will lead to lower healthcare costs overall as other forms of treatment are required to a lesser extent.

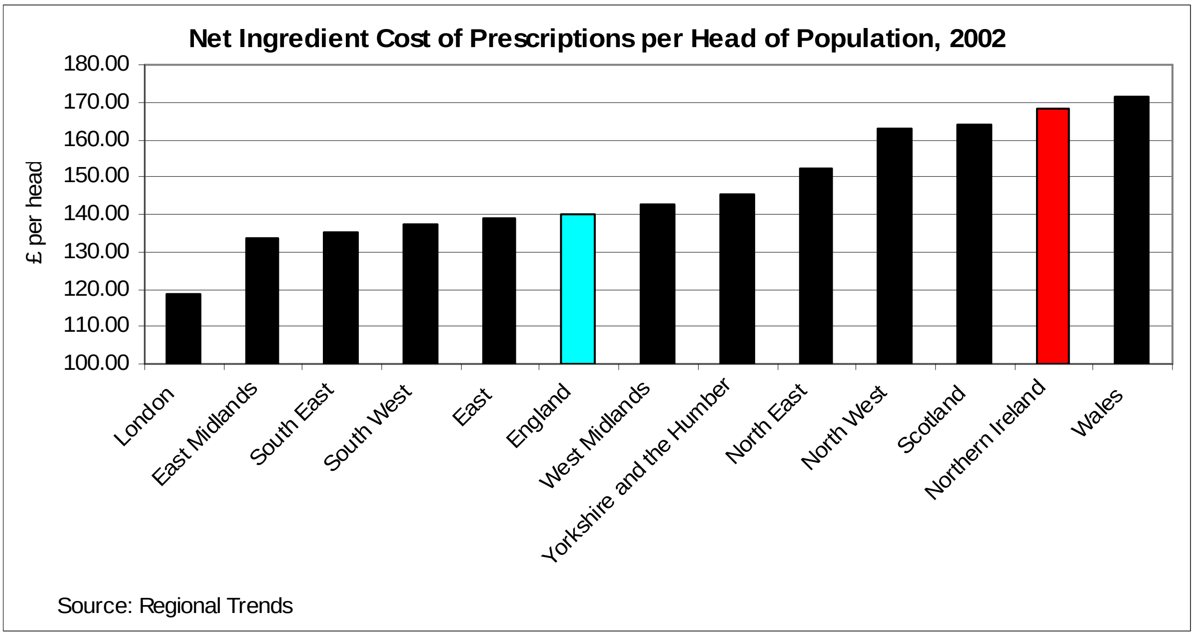
potential financial savings. The report allows practices to see how their prescribing compares to that of other practices in Northern Ireland and how they have changed compared to the previous year. The impact of using generic rather than proprietary drugs is emphasised.

All Boards have prescribing policies – these recognise any relevant regional strategic direction (e.g. a target in Priorities for Action) as well as Boards' own prescribing priorities. Once again, the Board prescribing advisers will take the lead in working closely with practices on these policies and may develop prescribing formularies for the practice to use as a tool to provide direction to practice prescribing where, for example, a problem has been identified with a certain type of medication

Overall, therefore, the interaction with GPs on prescribing is directed towards the provision of information and the application of persuasion and incentives as means of changing behaviour. There is currently no use of sanctions to influence prescribing practice. During the consultation process there were concerns expressed regarding this approach as GP's could make short-term improvements in order to obtain rewards and then return to past behaviour patterns before improving performance to receive further rewards in an ongoing cycle.

In 2003/04, £314m was spent on 26.6m prescriptions in Northern Ireland, 97% of which was paid for by the exchequer. Figure 3.18 below shows that Northern Ireland has the second highest spend per head on prescriptions of the UK regions

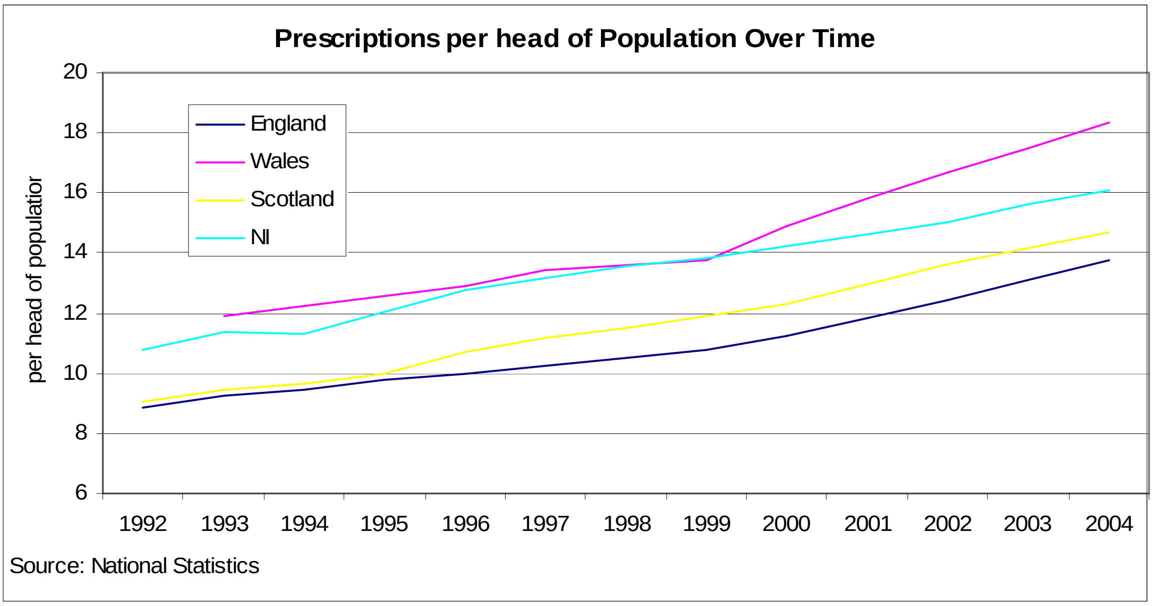
Figure 3.18: Net Ingredient Cost per Head of Population in Northern Ireland is the second highest of the UK regions.



Source: Regional Trends

In 2003, spend per head on prescriptions was 29% higher in Northern Ireland than England due to higher numbers of prescriptions being dispensed (+18%) and higher net ingredient cost per prescription item (+8%). It should be noted however that prescriptions in Northern Ireland tend to be in the less expensive forms of treatment, so that the differential in unit costs is significantly higher than that suggested by the headline figure.[55]

Figure 3.19: The number of prescriptions dispensed per head of population has increased by 43% over the past ten years in Northern Ireland compared to 46% in England.



Source: National Statistics

In addition, the number of prescriptions dispensed has increased by 48% over the past decade, so that the overall cost has increased by 131%. However, as figure 3.19 shows, Northern Ireland has had the slowest growth in prescriptions per head of the UK countries.

One of the main reasons for the higher unit cost of prescriptions in Northern Ireland relative to England is the greater use of proprietary drugs, which are on average over five times more expensive than generic drugs. In 2003, 41% of prescriptions dispensed[56] in Northern Ireland were for generic drugs compared to 55% in England. If Northern Ireland were to achieve the same generic dispensing rate as in England, this would reduce prescription costs by 18% equivalent to £55m. In terms of the number of prescriptions per head, over two-thirds of the differential with England is due to just five classes of drugs [57]

As part of the £474 DHSSPS Efficiency Programme [58] £83m is due to be saved over the period 2005/06-2007/08 by abating the growth in pharmaceutical costs through a

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[55] Based on analysis of 2002/03 figures for NI and England Cost Weighted Activity Index which showed unadjusted unit costs to be 18% higher in Northern Ireland and 29% higher once adjusted for differences in prescribing distributions between different types of drugs.

[56] DHSSPS state that there is no data available on generic *prescribing*

[57] Based on 2002/03 data 68% of the differential in prescriptions per head can be accounted for by Analgesics, Antibacterial Drugs, Hypnotics And Anxiolytics, Antidepressant Drugs and Ulcer-Healing Drugs which collectively account for 35% of prescriptions in Northern Ireland.

[58] The Chancellor's Budget speech in Spring 2003 announced a cross–cutting review of efficiency in the public sector to identify the scope for efficiencies in public spending. In his 2004 Budget, the Chancellor announced that the Government would set targets to achieve cumulative efficiency gains of 2.5% per year over the SR2004 planning period. The Secretary of State has decided that parallel reform and efficiency programmes should apply to the public sector in Northern Ireland. To ensure delivery of this substantial efficiency programme is achieved, departments have produced Efficiency Technical Notes (ETNs) providing specific and quantified information on the actions departments will take over the next three years to deliver their efficiencies.

number of initiatives. These include therapeutic tendering[59], repeat dispensing projects as well as the roll-out of Integrated Medicines Management[60] across the HPSS which to date, inter alia, has had a significant impact in reducing length of stay and readmission rates.

Conclusion

The overall impression from the consultation process was a lack of integration between GPs and the rest of the primary care sector. There was also significant frustration on behalf of GPs, related to the fundholding issue, that the Department and Boards did not appreciate their work, communicate sufficiently, or consider the views of GPs when setting policy. On the other hand, GPs were viewed as too often operating independently of other parts of the system (for example, in not appreciating the treatments that could be provided by Allied Health Professionals). Whilst the Department would clearly wish for GPs to have greater involvement with LHSCGs and multi-disciplinary working in general, there is clearly a problem with the general relationship GPs currently have with the DHSSPS and Boards..

It is important that there is clear understanding and common purpose between GPs and the rest of the health & social care sector. GPs not only provide an important service to the public, but, in their role as gatekeepers, influence the commitment of a significant amount of health care expenditure. Given the high levels expenditure on prescription drugs and attendances at A&E, it is crucial that this interface operates effectively. At the same time it is not clear that one of the main opportunities to stimulate reform (the revised GMS contract) has been taken - for example, in terms of the role that GPs have in managing the flow of patients into hospitals. The initial impression is that there has been significant cost with little benefit in terms of patient outcomes or GP morale[61].

> **Recommendation 17: An assessment should be carried out on the implementation of the GMS contract in Northern Ireland to examine whether the actual improvements in quality outweigh the cost. In light of the finding, the GMS contract should be revised as far as practicable**

Despite implementing various initiatives to reduce the problem, Northern Ireland still has a significantly higher level of spend on prescription drugs per head of population than the rest of the UK. As with the rest of the health & social care sector this can be linked in part to the absence of sanctions to dissuade poor performance.

> **Recommendation 18: New mechanisms involving greater use of sanctions are needed to tackle high prescribing costs and to encourage greater use of generic drugs.**

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[59] Treatment is prescribed from a clinical specification for medicine rather than the availability of individual proprietary drugs.

[60] Integrated Medicines Management involves re-engineering the system for medicines management covering the patient care journey by applying a dedicated clinical pharmacy programme complimenting medical and nursing input and developing a scheme for product standardisation across the primary and secondary care sectors.

[61] Although payment for QOF achievement points may improve morale the January 2005 survey of GPs indicated that 48% would be willing to receive less pay for a smaller workload whilst only 21% were happy with the revised GMS contract.

3.5 Personal Social services

Personal social services incorporate a broad range of activity, from residential and nursing home care, to domiciliary care and day care, meals on wheels as well as field social care services. Social services differ fundamentally from the rest of the health & social care system in that they are delivered through a collaborative combination of statutory, voluntary and private sector organisations. In addition, informal carers provide a crucial input into the system which is often taken for granted. Demographic trends mean that carers will require more support in the future as they themselves become increasingly elderly whilst policies for dealing with young carers remain underdeveloped.

Spending on personal social services in 2003/04 accounted for around a quarter of total HPSS spend (£680m). Of this, services for the elderly accounted for just over half (52%), with around 30% devoted to mental health services and 18% to family and childcare services. The main areas of expenditure related to the elderly in terms of nursing home places (£144m), domiciliary care (£92m) and residential home places (£68m). In comparison, the main spend category for childcare was social work (£41m) whilst residential homes (£34m) was the main area of spend on services for those with a learning disability.

In comparison with England, per capita spending on personal social services has been on average 15% higher in Northern Ireland over the past five years[62]. This is close to the estimated need for spending of 13% higher than England based on HM Treasury NAS methodology but considerably less than the figure of 44% implied by the Northern Ireland Executive revisions to the Treasury model.

In terms of outcome based measures of performance, whilst the community services target set out in the DHSSPS Public Service Agreement covering the period 2003-2006 focused on the number of care packages[63] delivered, the main emphasis subsequently has been on increasing the proportion of support delivered in people's own homes to 40%[64]. In terms of children's services, the main focus has been on increasing the adoption rate for children in need to 7%.

The 40% target is interesting because although only 38% of care packages are currently delivered in a domiciliary setting, there appears to have been a downward trend over the past decade with 50% of care packages in 1995 being delivered in a domiciliary setting. Whilst the number of domiciliary care packages has increased over time, the growth in the generally more expensive alternatives (nursing and residential care) has been greater. There is also significant variation between Northern Ireland trusts, with the largest provider of care packages, Homefirst, also having the lowest proportion (22%) of care packages delivered in a domiciliary setting - if removed, the Northern Ireland average rises to 41% and the target is met.

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[62] HM Treasury Public Expenditure Statistical Analysis .

[63] A care package is the main form of care that has been recommended for a client through the care management process. Care packages are provided in the form of places in nursing and residential homes as well as domiciliary care in persons own home. Separate services are also provided in terms of Home Help and Meals on Wheels as well as places at Day Care Centres.

[64] A 1999 study entitled "Attitudes and Aspirations of Older People: A Review of the Literature "for the Department of Work and Pensions found that 80% of older people would prefer to remain in their own home as long as possible.

Whilst the integration of personal social services is often perceived as being a key strength of the Northern Ireland system, this was not necessarily the view of those we consulted in the course of this Review[65]. In particular, it was felt that funding for social services was often diverted to shore up the acute sector. There was concern that this was creating longer term pressures as insufficient funding of social services would lead to delayed discharges from hospitals creating further problems in the acute sector.

These views are in line with the consultation responses detailed in the First Report of the Review of Community Care[66]. Whilst there was widespread commitment to the aspirations set out in the strategy "People First: Community Care in Northern Ireland for the 1990s"[67], which was introduced in 1993, there was concern regarding implementation. In addition, reservations were expressed regarding the considerable variations in service delivery across Northern Ireland whilst there were instances where the transition between hospital and care home was not as seamless as would be expected in an integrated system. Further, the decreasing share of domiciliary care was viewed as being the result of a perverse incentive as some of the cost of residential and nursing home packages can be offset be accessing social security benefits -which is not the case for domiciliary care[68].

The Review of Community Care highlighted that there were many good working examples of new and innovative practices in the area of community care. However, too much of this work was developed in isolation, and staff expressed frustration at the lack of collaboration between trusts. Fears were also expressed regarding the amount of resources available to community care - in particular, the fees paid to independent nursing homes.

The second phase of the Review of Community Care was to involve a number of projects taken forward on the basis of the "People First" objectives. In the three years since the publication of the first phase there appears to have been a significant amount of analysis and review carried out into particular aspects of the community care system. To date, however, with the exception of increasing the rate of payment to independent care homes, there also appears to have been few developments in terms of how services are actually provided. In addition, there is little to suggest that this position will change in the near future.

Given the variety of providers supplying personal social care, it might be expected that a degree of competitive pressure exists in the system. In practice, however, there is concern that the public sector is crowding out the independent sector. For example, although independent/voluntary providers are able to tender for contracts to deliver care packages, they have difficulty in recruiting sufficient amounts of staff because of the higher salaries and greater certainty of employment offered by statutory providers. Therefore, even where independent provision may be preferable

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[65] Views ranged from those who argued that any additional funds tended to go to the acute sector to those who suggested that funds were actually taken from social services.

[66] DHSSPS, 2002

[67] Objectives included, the development of services to enable people to live in their own homes wherever possible, provision of practical support for carers, proper assessment and good case management, promotion of the independent sector alongside good quality public services, clear delineation of the responsibilities of agencies, and securing better value for taxpayers money.

[68] In the UK, local authorities levy a charge for domiciliary care so there is less of an incentive to use the more costly care home alternative.

in terms of service and cost, the contract may be lost due to staffing shortages. There was also resentment expressed that independent providers incur the expense of training staff who then move to the more highly paid public sector.

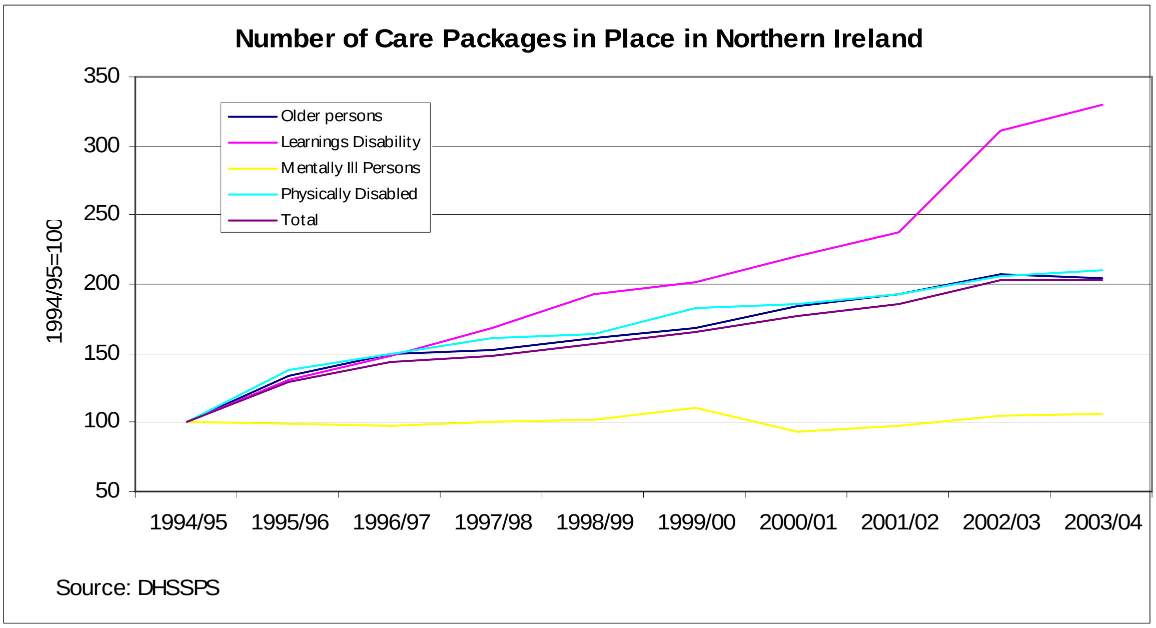
Assessing the efficiency of the delivery of social services is more difficult than for health care because the public sector is not the only provider, so inputs are less easily related to outputs. In addition, the comparability of data between jurisdictions is even more difficult than for healthcare. Therefore the analysis set out below is necessarily more tentative than in previous sections.

3.5.1 Adult Services

Adult services cover a wide range of service provision by trusts to a range of client groups, although services to the elderly dominates, accounting for three quarters of all care packages. Each trust decides the mechanisms for the delivery of social care. As at December 2004 there were 19,654 community care packages in effect, 38% of which were in nursing homes, 24% in residential homes and the remainder in the form of domiciliary care. The private sector provides the overwhelming bulk of nursing home packages (94%) and nearly half (47%) of residential home places. Over the past five years, whilst the number of care packages has increased by 29% overall, nursing and residential home packages have increased by over 40% whilst domiciliary packages have increased by only 12%.

Figure 3.20 shows that over the longer term there has been even greater growth in the number of care packages provided with the exception of mental health where the level of provision has remained broadly stable over time. This is in line with the views those whom we spoke to representing mental health services who were concerned that mental health services were being left behind.

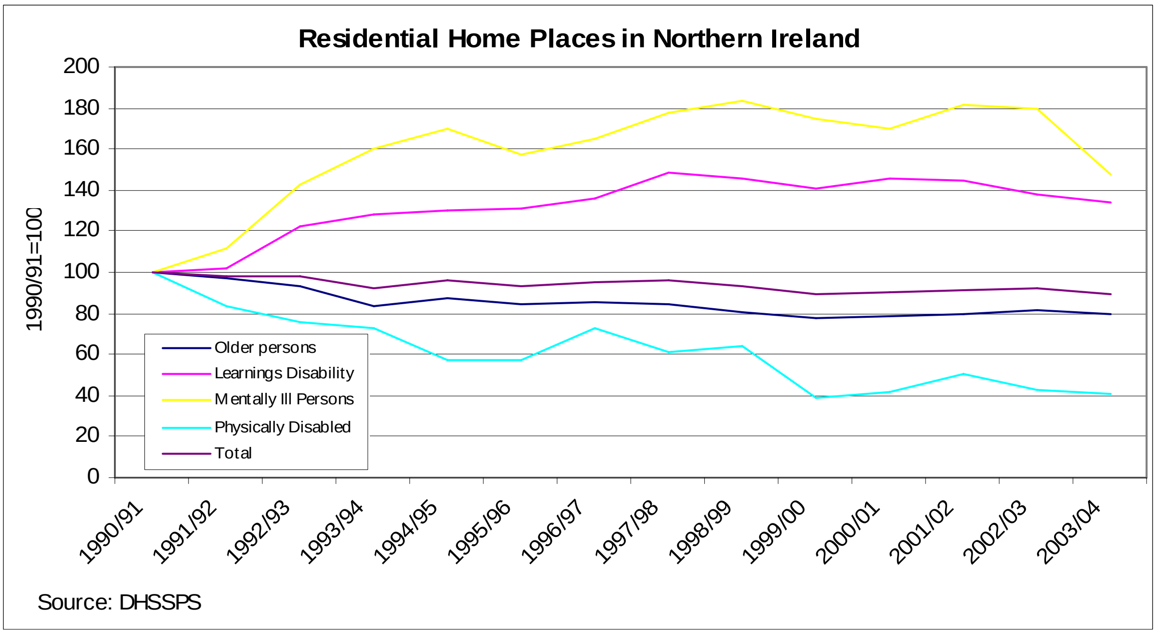
Figure 3.20: The number of care packages has more than doubled over the past ten years.



Source: DHSSPS

Although the number of residential care packages has risen over time, the number of places in residential homes has fallen as shown in figure 3.21:

Figure 3.21: There has been a 11% fall in the residential home places in Northern Ireland since 1990/91



Source: DHSSPS

The number of available places in residential homes in Northern Ireland has been on a gradual downward trend since 1990/91, and now stands at 6,282 (2003/04). Three quarters of places are in homes for older persons whilst places for persons with a learning disability account for 18% of the total. Figure 3.21 shows that the largest growth in places was in homes for the mentally ill and the greatest decline was in homes for physically disabled persons.

In comparison with other parts of the UK, there are 12.4 places in residential and nursing homes per 1,000 adult population in Northern Ireland compared to 13.8 in England, 12.0 in Scotland and 12.8 in Wales. However, given that the main client group for residential and nursing homes places are the elderly, the 2002 Needs and Effectiveness Evaluation quoted figures in terms of the population aged 65 and over which implied that there was 10% greater provision in Northern Ireland than England, whilst the 2002 Review of Community Care presented comparisons in terms of those aged 75 and over which implied that there were 15% more places in Northern Ireland than in England.

In terms of non-residential care, as of March 2004, 26,400 people in Northern Ireland were receiving home help, 4,650 meals on wheels services and 10,300 were registered at day care facilities. However, there is a downward trend in the numbers receiving home help, whilst numbers receiving meals on wheels and registered at day care facilities has risen over time. There are also significant variations between trusts with, for example, 59% of people aged 75 and over in the Armagh & Dungannon Trust receiving home help services compared to only 22% in the Ulster Community and Hospital Trust.

Those involved in mental health services raised a number of concerns with this Review that this form of care had a low priority in terms of resources, despite the pressures that mental health problems have on patients and their families - it is only when a major incident occurs that mental health is considered. There was also difficulty in getting someone to take responsibility for a particular mental health issue as delivery of mental health services is spread across a range of organisations - this was a general point made by those representing the other forms of social services provision too.

In addition, despite the policy aim that long-term care should no longer take place in psychiatric hospital environments, the view of those we spoke to was that resources had not yet been transferred to the community sector to the same extent as in England. Although some progress has been made - with spend on the provision of mental health services in a community setting increasing at a faster rate than for psychiatric hospitals - the community share of mental health spend is still lower than was the case for England in 1999/00.

The Review of Mental Health and Learning Disability published a draft report in June 2004 and highlighted the higher level of need for mental health services in Northern Ireland (linked to social deprivation and political conflict). The draft report sets out a new Strategic Framework for Adult Mental Health Services for the next 15-20 years. Highlighting that there is insufficient investment in community services, leading to an inappropriate over-reliance on hospital services, the draft report makes recommendations covering the need for:

- better community and primary care for people presenting with a mental health problem;
- improved team working in community mental health services;
- improved services for those experiencing a crisis, with these services acting as a gatekeeper to hospital services;
- the location and quality of hospital provision;
- promotion of recovery and rehabilitation services to ensure people do not remain in hospital unnecessarily; and
- assertive outreach teams for those who remain vulnerable in the community.

Many of the themes expressed in terms of mental health can also be applied to learning disability and physical & sensory disability, in particular, the lack of progress in transferring provision from a hospital to community setting. Demand for services for the disabled is increasing due to rising survival rates of those with profound and multiple disabilities, whilst legislative requirements also have significant - in some cases disproportionate - resource implications. In addition, as with other social services, the view of those we spoke to was that policy initiatives in England were not being replicated in Northern Ireland.

The only significant indicator of the extent to which social services are delivered efficiently is unit costs. However, whilst variation in unit costs between trusts may provide an indication of relative efficiency, it may also reflect differences in underlying costs and quality of service. Overall, there appeared to be a significant variation in unit costs between trusts, for example, the cost of social work for the elderly in the North & West Belfast Trust was 220% higher than the Northern Ireland average whilst the cost of care homes for the elderly was significantly higher in the Causeway Trust.

3.5.2 Children's Services

Social services provided to children include child protection, care of looked after children (including fostering and residential care services), adoption services and day care facilities. Social work accounts for just over a third of total spend on children's services, with a fifth spent on residential homes and 15% on fostering and adoption services.

The key issue with respect to children's services is the level of funding relative to England. In particular, concern was raised with this Review that funding is to be terminated for the projects under the Children's Fund established by the Northern Ireland Executive. In addition, the perception was that policy decisions take longer to reach and implement than in England, with the result that service provision is often years behind in Northern Ireland - again, similar views were expressed in respect of the other social services.

However, from the activity statistics and evidence presented in the Needs and Effectiveness Evaluation, it appears that service provision is broadly similar Northern Ireland and England in terms of the proportion of children looked after by local authorities or on the child protection register - although it could be argued that that provision should be higher given deprivation levels in Northern Ireland.

Therefore, the main reason for the relative level of spend is lower unit cost of provision. Lower unit costs may reflect lower quality of provision or it may be that social services for children in Northern Ireland are provided more efficiently than in England. To the extent that the latter is the case, this raises questions as to whether similar levels of efficiency could not be derived for other parts of the health & social care sector.

There are currently around 2,500 looked after children in Northern Ireland (in the sense that a trust has parental responsibility for them). This is equivalent to 5.7 children per 1,000 population aged under 18 compared to 5.5 for England and 5.4 in Wales. Around 61% of children looked after are in foster care, 13% in residential care and the remainder placed with their families or elsewhere - the split in provision is similar to that in the rest of the UK. There are around 1,400 children on the child protection register - mainly as the result of neglect or physical abuse. A greater proportion of the population aged under 18 are on the child protection register in Northern Ireland (0.32%) compared to England (0.23%).

The quality of provision appears slightly better in Northern Ireland, with looked after children and young people experiencing more placement stability than in England or Wales, whilst in 2001/02 the proportion of young people aged 16 or over leaving care with at least one GCSE or a GNVQ was slightly higher in Northern Ireland (44%) than in England (41%)[69].

As with adult services however, there are significant variations across trusts in the level and type of provision. For example, there was a 124% higher rate of looked after children and 446% more children on the child protection register in the North &

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[69] Five per cent of looked after children in NI had 3 or more separate placements during 2001/02 compared to 13% in Wales and 15% in England.

West Belfast Trust than the Craigavon & Banbridge Trust, whilst there were 137% more day care places in the South & East Belfast Trust than in Foyle. Such variations are largely explained by variations in need. However. there were also marked difference in the unit costs of residential care. For example if the unit cost of provision achieved by the South & East Belfast Trust was replicated across Northern Ireland, then the overall cost would fall by almost a quarter.

Conclusion

The main issue raised by those we consulted during this Review with regard to both adult and children's social services was a perception of too little funding, and, in the opinion of many, in large part due to resources being diverted to the acute sector. Whilst the evidence was mixed in terms of funding, the available data does not tend to suggest that there is a significantly lower level of social services *provision* in Northern Ireland relative to England. That is not to say that there are specific areas where there are insufficient resources or that a case could be made for a higher level of provision given relative levels of deprivation.

In addition, innovative projects tend to be resourced through non-recurrent funding so that they are more likely to be terminated in the face of overall funding pressures. There needs to be a more rigorous approach taken to ensure that if projects are discontinued, it is on the basis of relative effectiveness.

The funding issue was directly linked to the integrated nature of the service. Northern Ireland appears currently to be mid-position between full integration - where responsibility for both hospital and social services is shared - and the position in the rest of the UK where services are split. The findings of the Community Care Review would suggest that it is not only funding but also the movement of patients between services where the link is less than seamless. This Review has not been able to come to a conclusion as to whether the answer is to have greater integration or to formally split health and social services - whilst the link was considered worth maintaining by those to whom we spoke, in light of the associated problems it was not entirely clear why this was the case.

The above has been only a brief overview of the key issues associated with the provision of social services in Northern Ireland which, given the issues highlighted, merits a more fundamental consideration, with a focus on the services delivered and in particular the equity of provision between different parts of Northern Ireland.

> **Recommendation 19: the integration of health & social services should be re-examined with an initial first stage being the ring fencing of funding for social services from the acute sector. There should however be scope for financial sanctions when inefficiency in one part of the system impacts negatively on another e.g. lack of social services provision causing delayed discharge from hospital.**
>
> **Recommendation 20: the contracting of services from independent/voluntary organisations should be reviewed to consider whether it can be placed on a more strategic basis.**

3.6 Waiting and access

For public services free at the point of use, waiting has been one way of rationing or delaying access and hence aligning demand and supply. However, while waiting, in the absence of prices, may have a legitimate role in rationing scarce resources (given a fair waiting system), long waiting lists and times are not just a product of finite budgets. The existence of very long waiting times in Northern Ireland compared with England and Scotland, and variations in waiting times within Northern Ireland suggests considerable scope for improving Northern Irish patients' experience of waiting within current resource limits.

Although the numbers of patients waiting can be small in comparison to total activity in the health and personal social services, long waiting times can not only be damaging to patients' health but also increase costs of care. Conversely, the benefits of successfully reducing waiting times are not only reflected in better patient experience of their care (and better health) but also in more efficient health and social services.

In particular, we review data highlighting variations in waiting lists and times - between geographical areas, trusts and specialties. The existence of variations can be a sign of hope - long or excessive waiting may not be an inevitable consequence of the way the system is funded, for example. On the other hand, variations - for example, *within* a system - may suggest that resources are not being used optimally. Moreover, variations can also suggest that the problem is concentrated rather than dispersed across the whole system and hence suggest that particular policies will be more effective than others in tackling the problem.

3.6.1 Scale of the problem

Amongst the four parts of the UK, Northern Ireland has some of the longest waiting lists and times for inpatients and outpatients. Here we set out the scale of the problem, starting with waiting to see a specialist in an outpatient department through to waiting for admission to hospital and delays in discharges and waiting for other health and social care services.

Box 3.2: Measuring waiting times

How long patients wait can be measured in two different ways: a census (or snapshot) of the length of time patients still on the waiting list have waited; the actual length of time patients waited prior to seeing a specialist in outpatients or being admitted to hospital as an inpatient or day case.

Both ways of measuring waiting are valid, but provide different perspectives on waiting. However, from the patient's point of view, the main concern will be how long they waited having been seen at outpatients or having been admitted into hospital.

While patients who have been to outpatients or have been admitted may be seen relatively quickly, this may give a misleading impression of the way waiting lists are working or being managed.

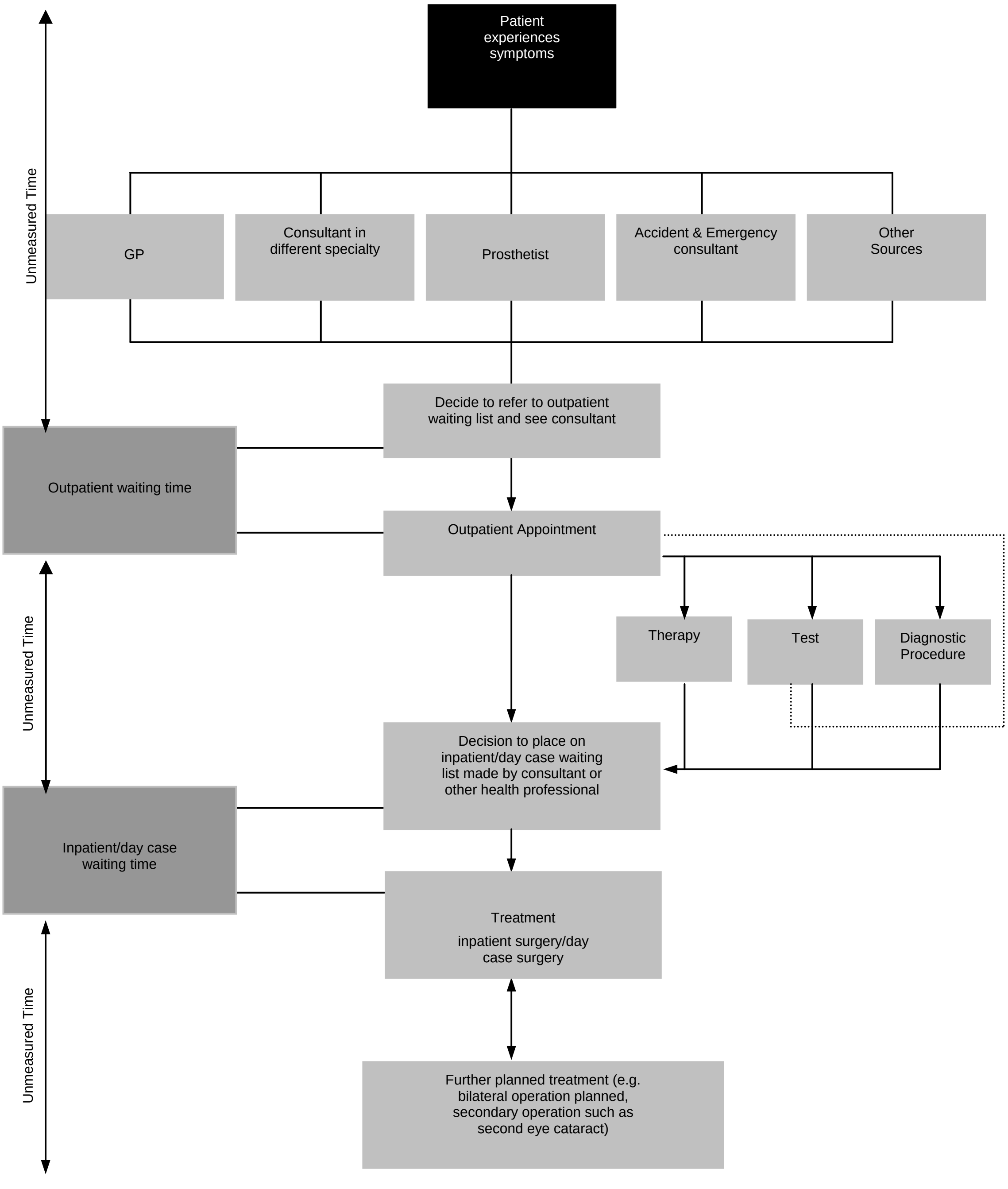
For example, as waiting lists do not operate as strict queues (on a first come, first served basis), but with patients moving around the list depending on changes in the urgency of their condition, the census view of waiting can reveal whether a group (of presumably less urgent cases) are continually bypassed by more urgent patients. The bypassed patients can end up as a 'mortlake' of patients who may never reach the head of the queue.

Box 3.3: The actual waiting experience.

Official waiting time statistics in Northern Ireland (and indeed in other parts of the UK) do not capture the full waiting time experienced by patients from the time they experience symptoms to the conclusion of treatment. The patient's journey through the health care system, for example, is illustrated in the chart below which shows where the gaps exist in official recording of waiting.

As noted in Box 1, above, the way that waiting lists operate within outpatients and inpatients can also have a significant impact on some patients overall waiting times.

The patient journey and reported waiting times

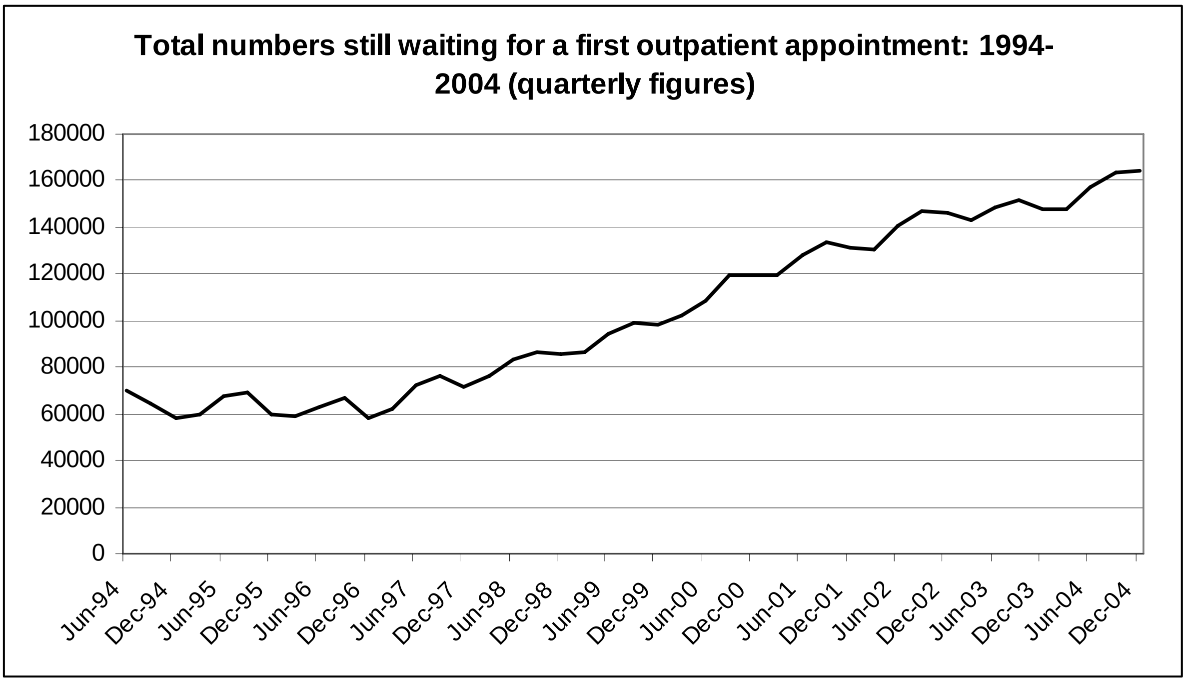


Source: NHS Waiting Times in Wales Volume 1 The Scale of the Problem, National Audit Office Wales

3.6.2 Outpatient waiting

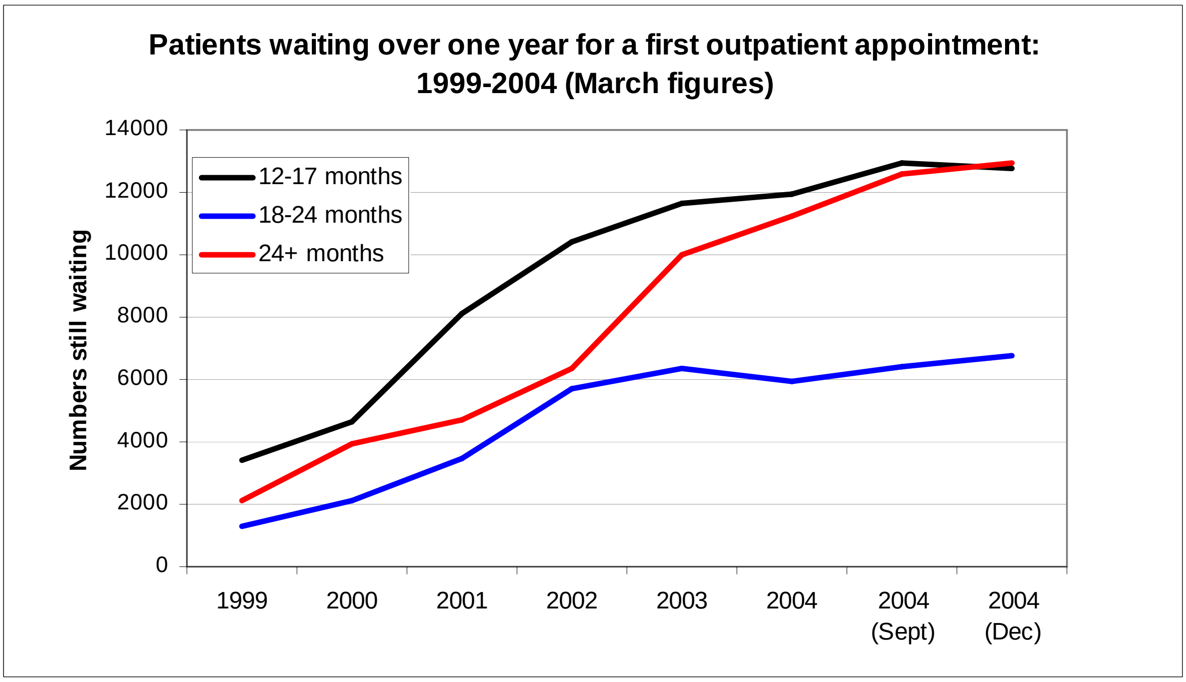
The total number of patients still waiting for an outpatient appointment in December 2004 stood at nearly 165,000. Trends over the last five years have been inexorably upward, and have risen by around 150% since 1994 (see figure 3.22). Nearly one in ten of the total Northern Ireland population is currently waiting to attend for a first outpatient appointment.

Figure 3.22: Total numbers of patients still waiting for a first outpatient appointment have increased by over two and a half times since 1994.



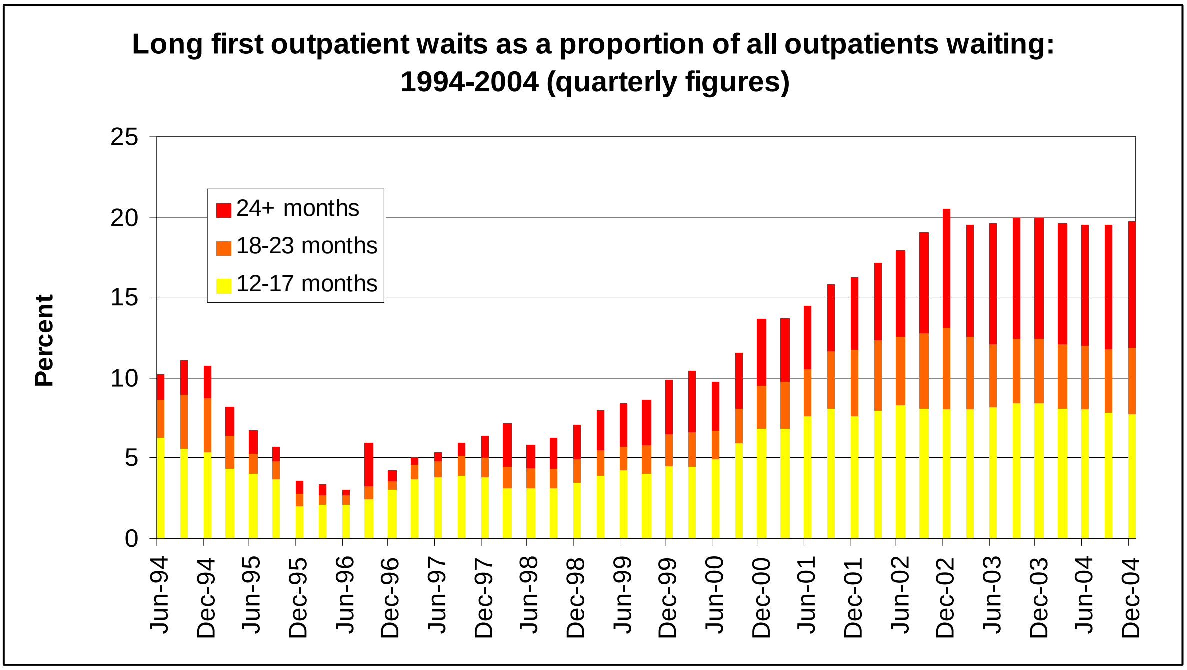
Of more concern to patients is how long they have to wait rather than the length of the queue in front of them. Over the last five years, ‘excessive’ waits (of more than a year) have risen. The number of people waiting 12-17 months has increased three-fold; those waiting 18 to 24 months four-fold, and those waiting over two years, six-fold (see figure 3.23).

Figure 3.23: Numbers of patients waiting over one year for a first outpatient appointment have risen over four-fold between 1999 and 2004.



While those waiting over a year have, since 2002, levelled off, there are no signs of any reductions in the numbers of excessive waits and 1 in 5 people are still waiting over a year for their first outpatient appointment (see figure 3.24.

Figure 3.24: Although the increase in the proportion of patients waiting over a year for a first outpatient appointment has levelled off recently, nearly one in five are still waiting more than a year and nearly 1 in 12 are waiting over two years.



The reasons *why* the number of long waits has increased over the last ten years are explored below. However, it seems unlikely that waits have increased either because of lack of funding - spending has increased considerably over the last ten years; or due to increases in demand - between 1996 and 2002/3, total outpatient attendances rose by just 5% - around 0.5% per year on average.

3.6.3 Variations in outpatient waiting times

Apart from variations in waiting times over time, waiting times also vary among specialties, hospitals and in comparison to Wales, Scotland and England.

Variations by hospital

As figure 3.25 shows, there is considerable variation across hospitals in the share of the total outpatient waiting list across Northern Ireland. Of course, the main explanation for this is the variations in sizes of hospitals and workloads - bigger hospitals will have larger lists. However, as figure 3.26 shows, some hospitals - such as the Royal Group, Green Park and Ulster Community - appear to have a higher share of the total outpatient waiting list than might be expected given the number of GP referrals received.

Figure 3.25: Just three hospitals account for nearly half of the total number of patients still waiting for a first outpatient appointment

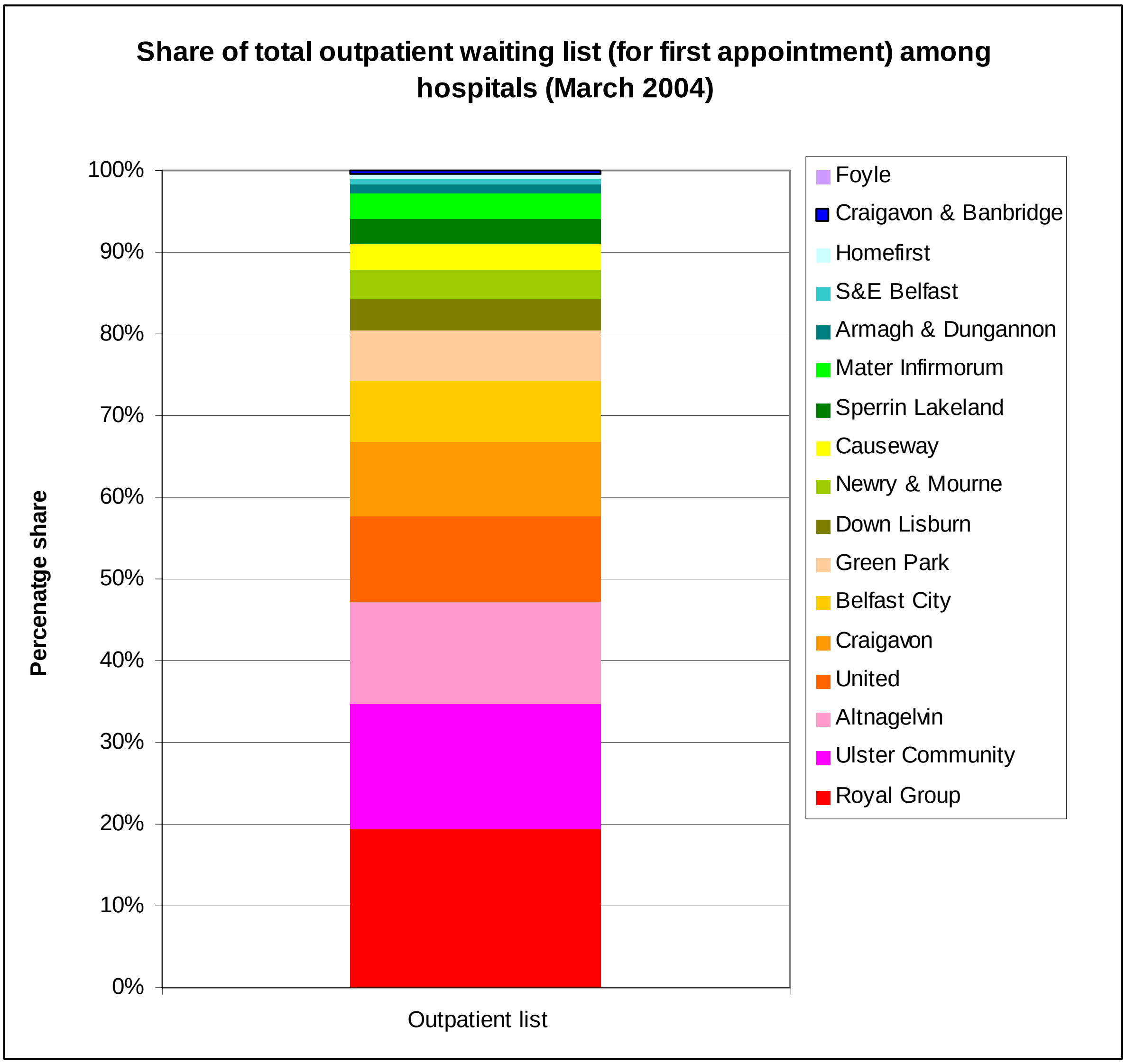
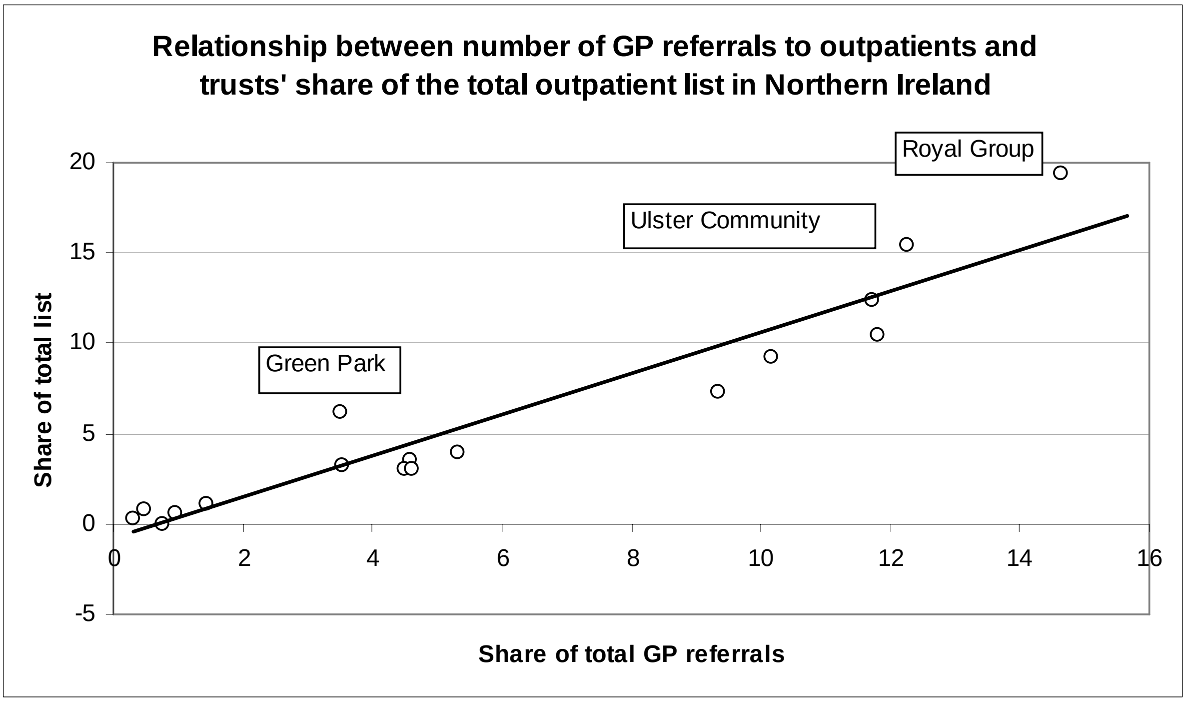


Figure 3.26: Some hospitals have a higher share of the total outpatient waiting list than might be expected given their share of total GP referrals to outpatients



As already stated, however, of greatest concern to patients is the time they have to wait rather than the total size of the list. And as figures 3.27 and 3.28 show, there are significant variations across hospitals in the proportion of those patients waiting over a year and over two years for admission.

Some variation is perhaps to be expected given differences in the sizes of hospitals, local pressures and circumstances. However, as figure 3.29 shows, there is a relationship between trusts' shares of total GP referrals to outpatient departments and their shares of the number of patients waiting over 12 months for a first appointment. However, some hospitals - such as Ulster Community, Green Park and the Royal Group - appear to have a greater share of long wait patients than might be expected given their share of referrals.

Figure 3.27: Over a quarter of patients in two hospitals are waiting more than a year for their first outpatient appointment

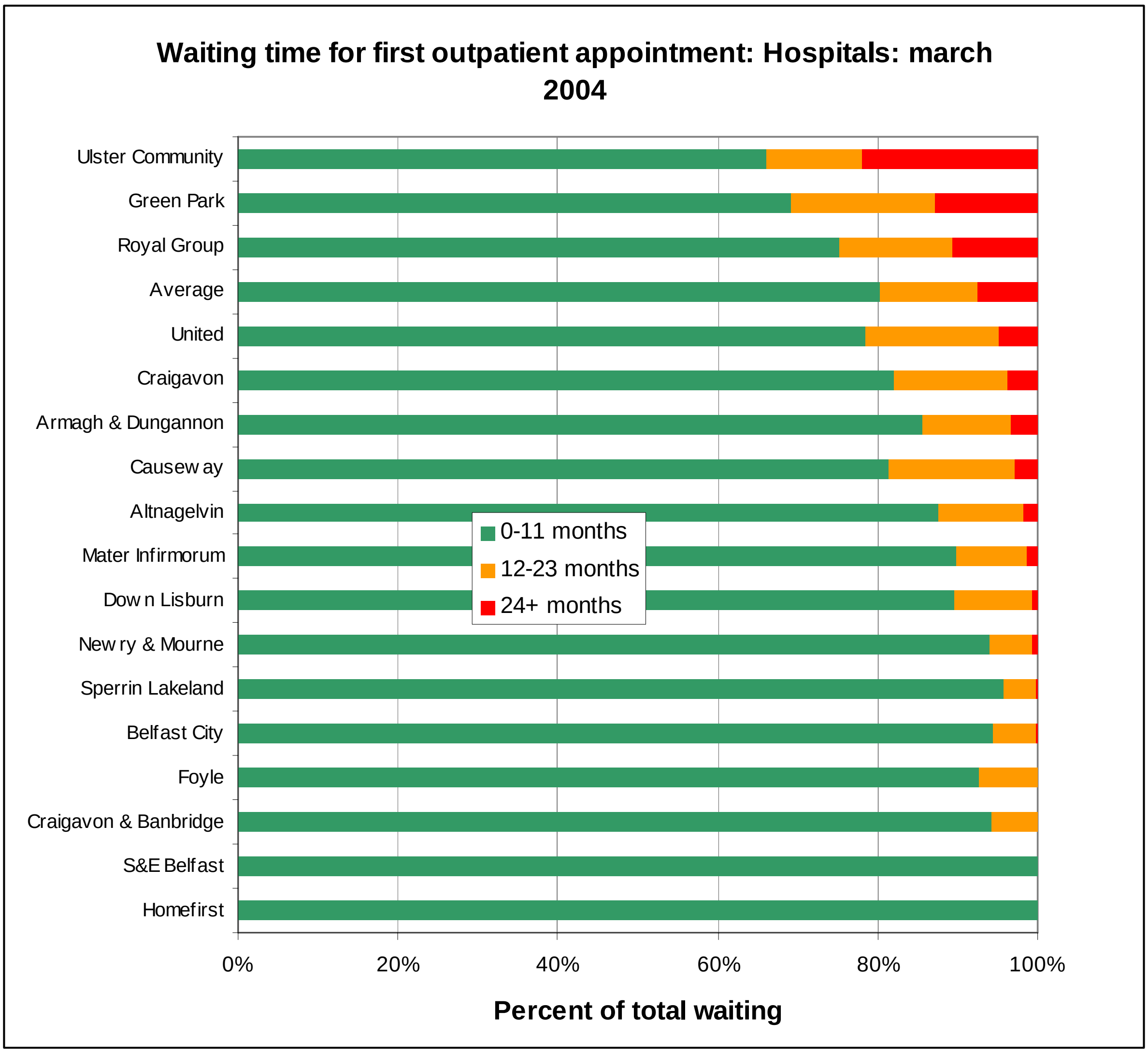


Figure 3.28: Just two hospitals account for 70% of patients waiting over 2 years; five hospitals account for 70% of patients waiting 12-23 months…

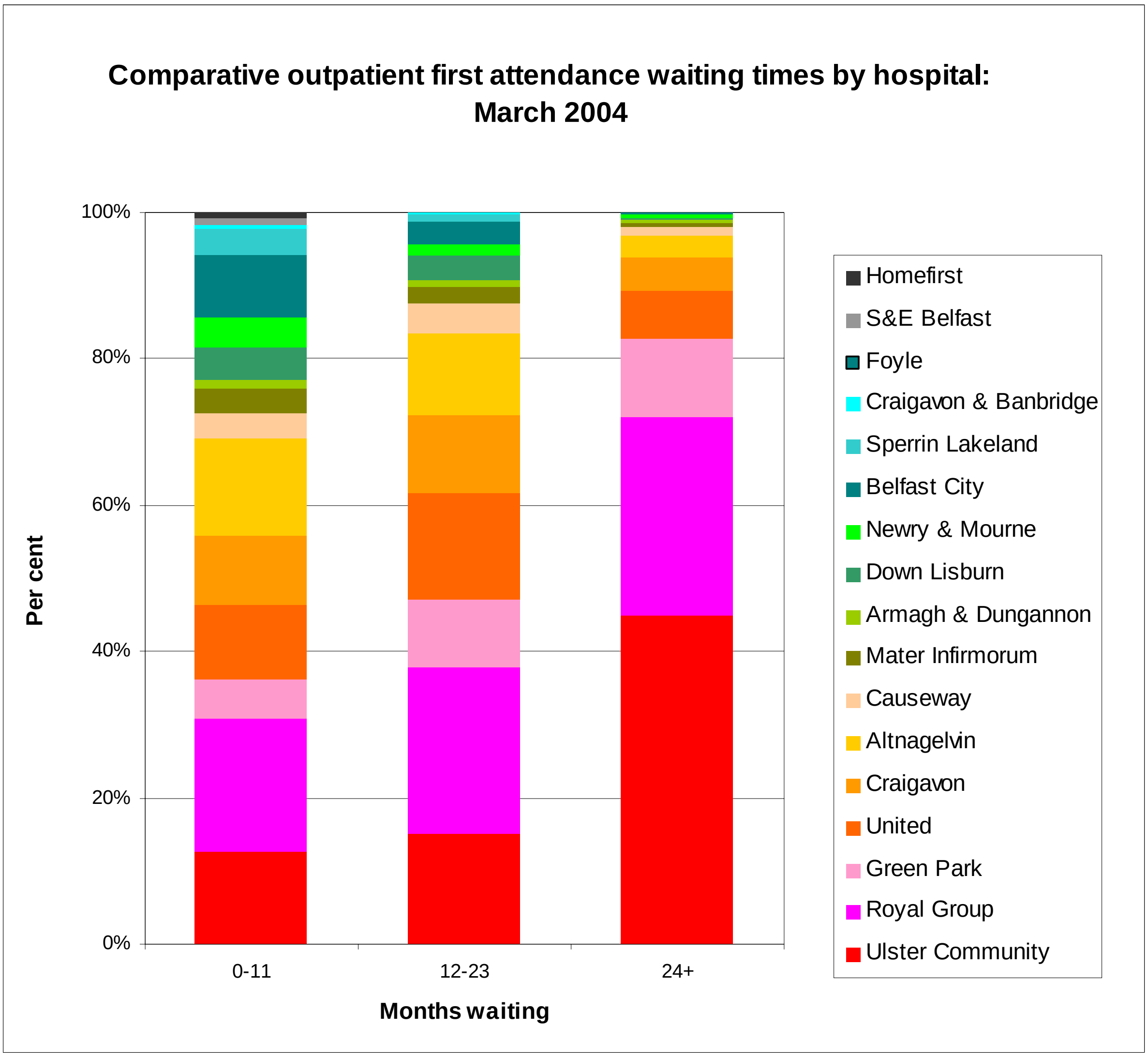
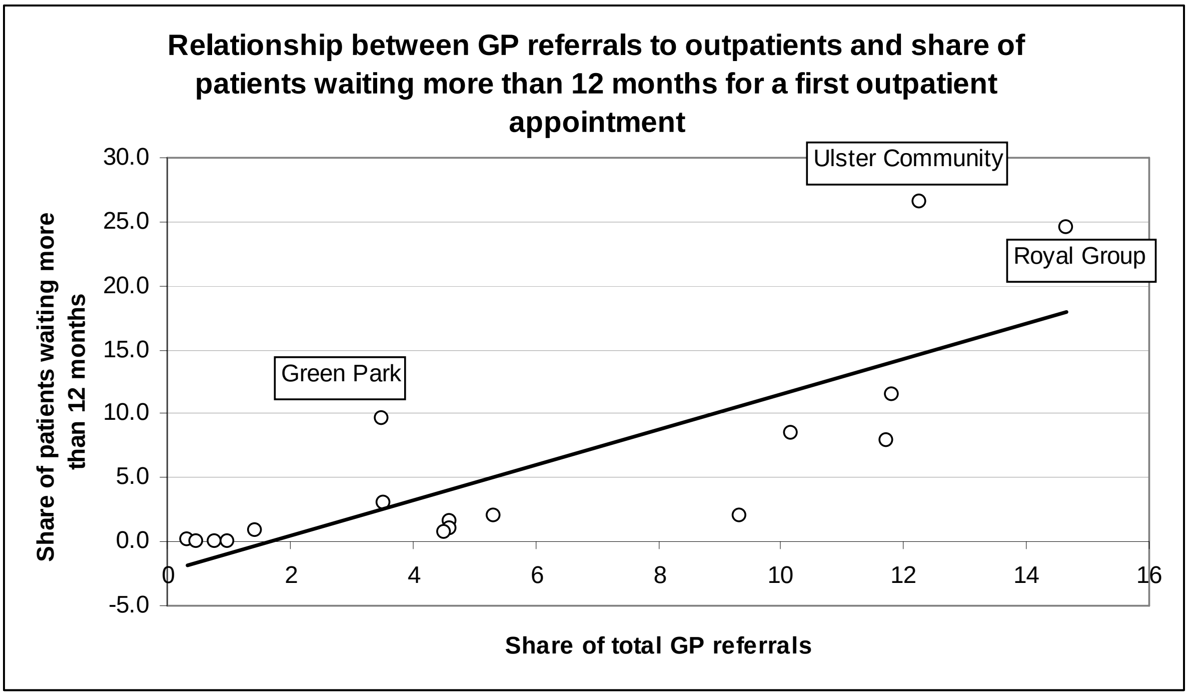
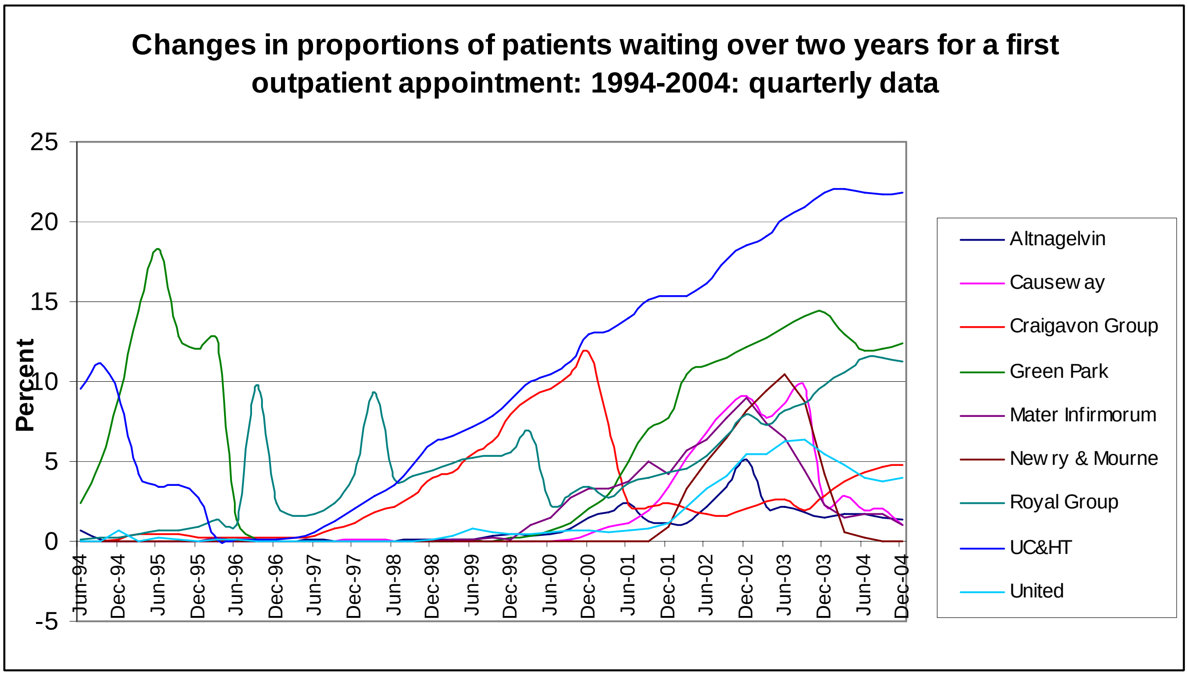


Figure 3.29: Some hospitals have a higher share of the total number of patients waiting more than one year for a first outpatient appointment than might be expected given their share of total GP referrals to outpatients



However, the fact that some hospitals have managed, for example, to virtually eradicate very long waits of over two years while others, with similar proportions waiting over two years in 2002, and although making big reductions over the last two years, have not, suggests that not all the variations in waiting times across hospitals are justified (see figure 3.30).

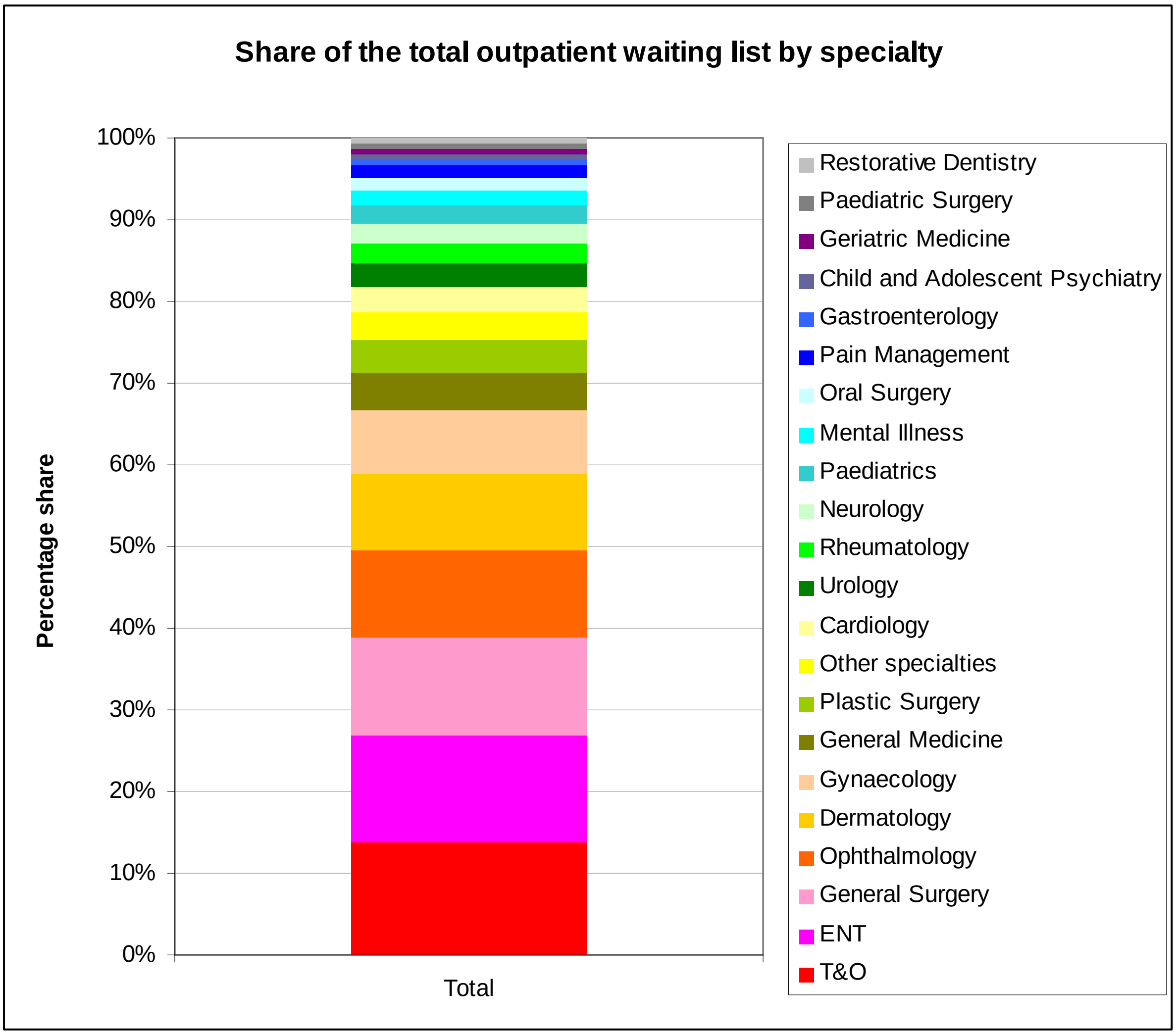
Figure 3.30: Some hospitals have reduced the proportion of very long waits for outpatient appointments; others have not.



Variations by specialty

Again, as might be expected, there are variations in waiting lists and times across specialties (see figures 3.31, 3.32 and 3.33). And again, much of this variation will be expected given variations in, for example, workloads.

Figure 3.31: Just four specialties account for almost half of all those waiting for a first outpatient appointment in September 2004



However, it is very noticeable that just two specialties - plastic surgery and trauma and orthopaedics - account for over six out of ten patients waiting more than two years for a first appointment in outpatients (see figure 3.32). For plastic surgery in particular, over 60% of patients are still waiting for a first appointment after two years (see figure 3.33).

Figure 3.32: Just two specialties account for over 60% of patients waiting over 2 years for a first outpatient appointment; five specialties account for two thirds of all patients waiting 12-23 monthS

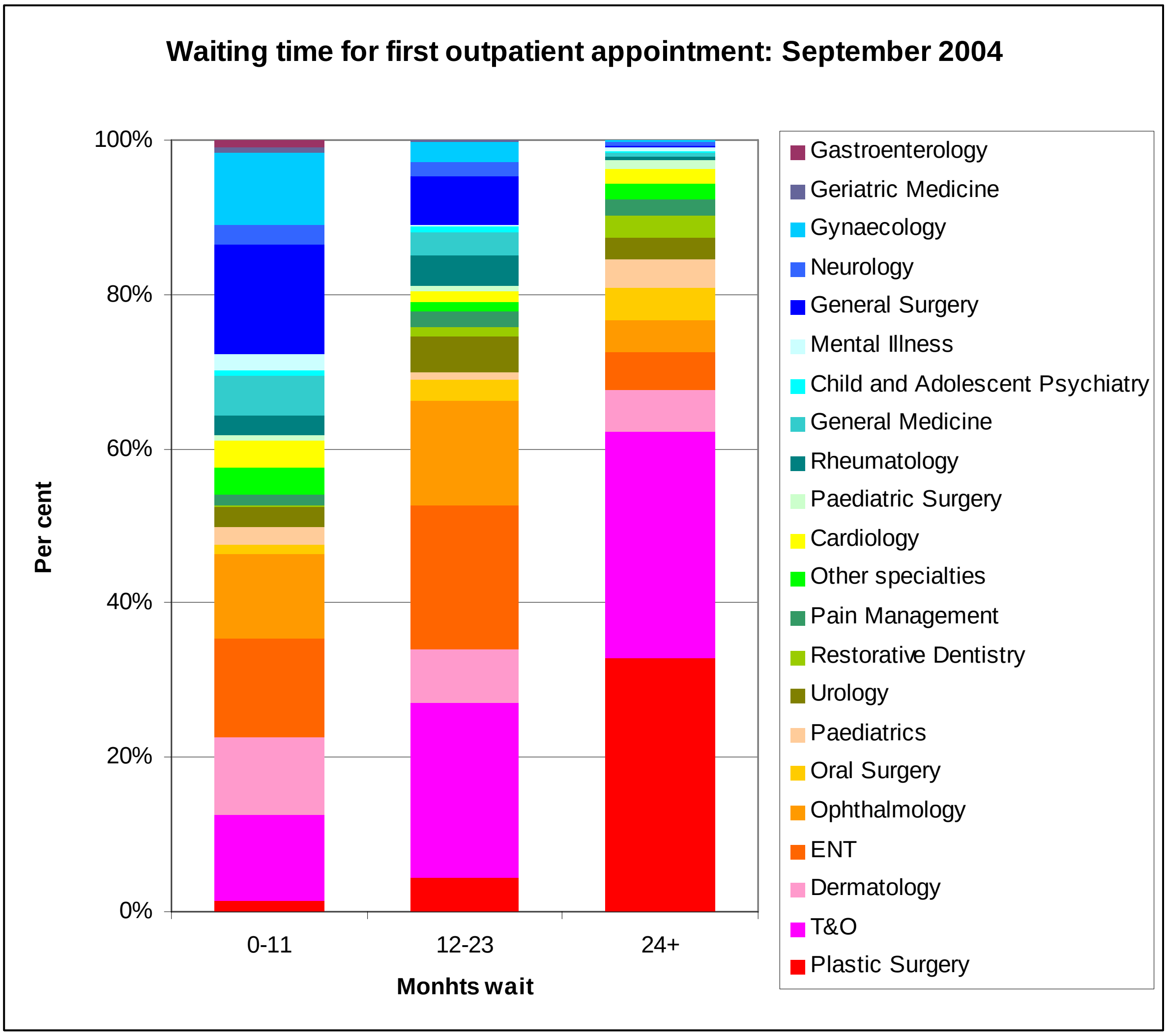
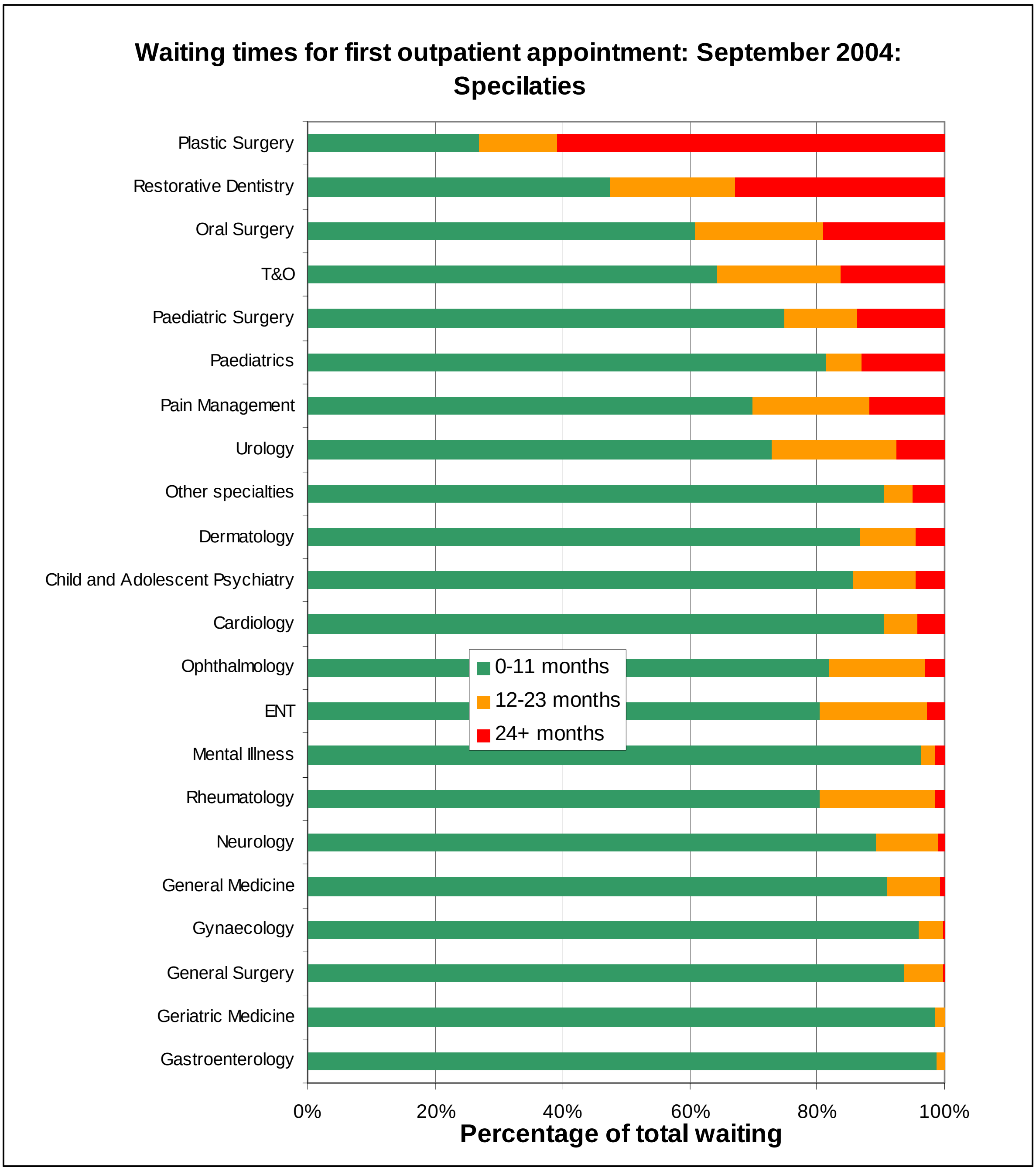
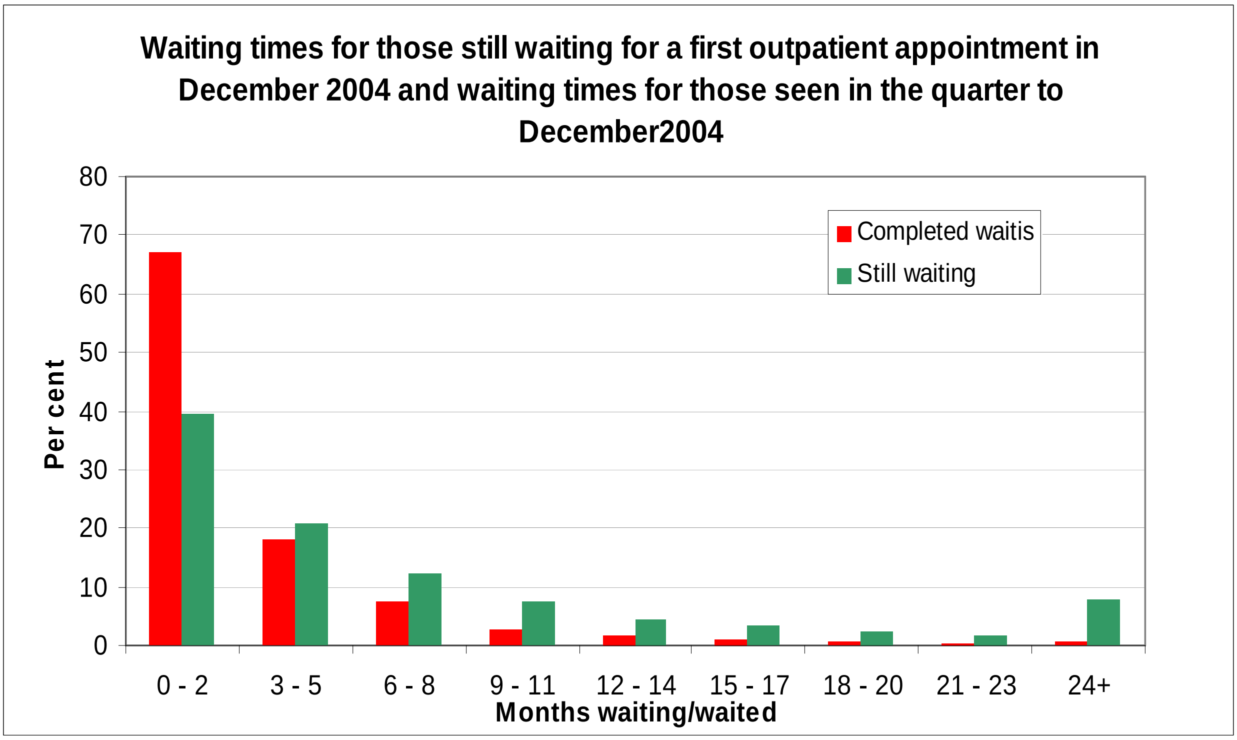


Figure 3.33: Six out of ten Plastic surgery patients are still waiting over two years for a first outpatient appointment; Outpatient waiting time variation among specialties



Another view of waiting is the length of time patients waited once they had had their first outpatient appointment. Figure 3.34 shows a marked difference in the waiting times distributions for those with ‘completed’ waits and those still on the waiting list. While just over 65% of those who did have an appointment only waited up to two months, the corresponding figure for those still waiting is 40%.

Figure 3.34: Patients who have had a first appointment tend to have waited less time than those still on the list. This is partly due to under 3 month waits being under-recorded by the quarterly census of those still waiting, but may also indicate a 'mortlake' of bypassed patients.



Variations across the UK

Comparisons of outpatient waiting lists and times across the UK are difficult to make due to lack of data. Scotland, for example, has no live outpatient list, rendering comparisons with Northern Ireland impossible. And no data is collected in England on the total numbers waiting.

However, figures 3.35 and 3.36 make what comparisons are possible - mainly with Wales. On all the comparisons that are possible, Northern Ireland has the poorest performance, with longer lists per head of population than Wales, proportionately more patients waiting longer than six months (38%) than either England (probably around 1%) or Wales (31%), and far more proportionately waiting over 18 months (12%) than Wales (3%).

Figure 3.35: Northern Ireland has more patients waiting for a first outpatient appointment per head of population compared with Wales and England

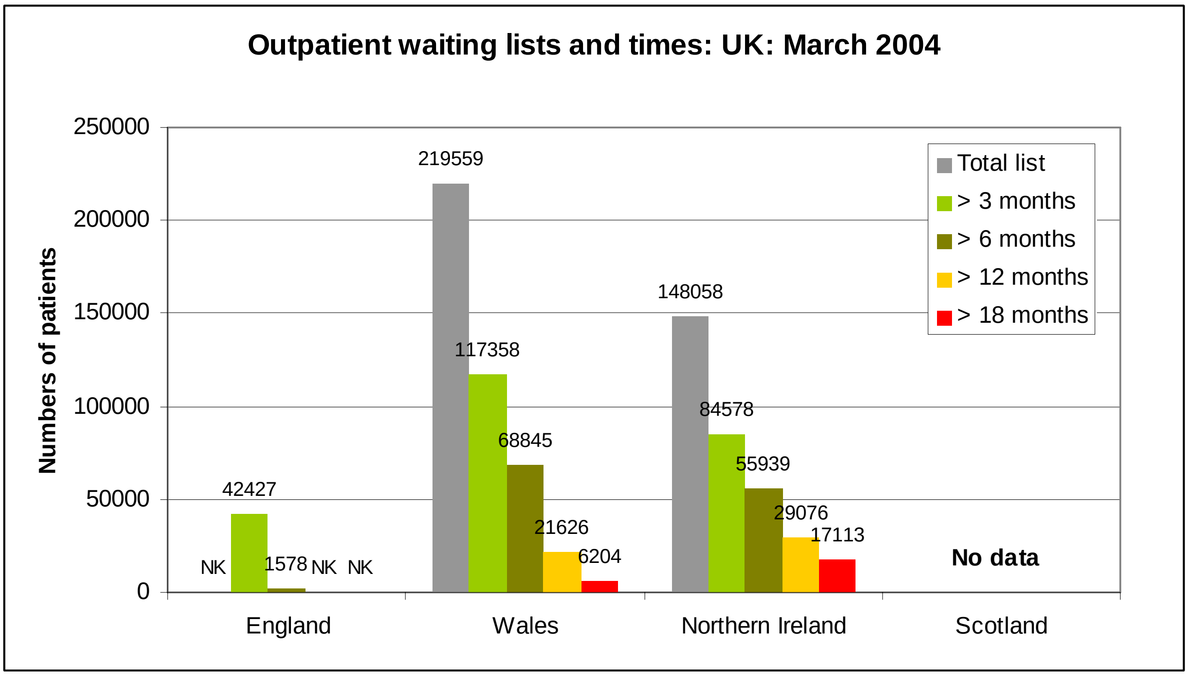
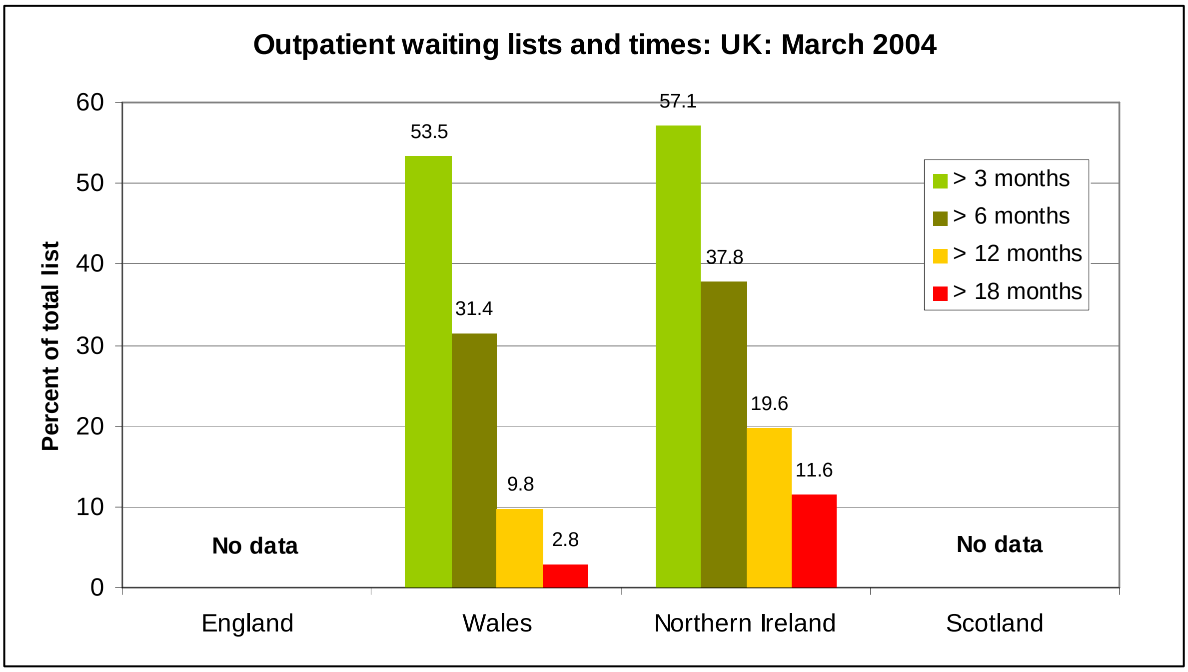


Figure 3.36: Northern Ireland performs poorly on outpatient waiting times compared with Wales

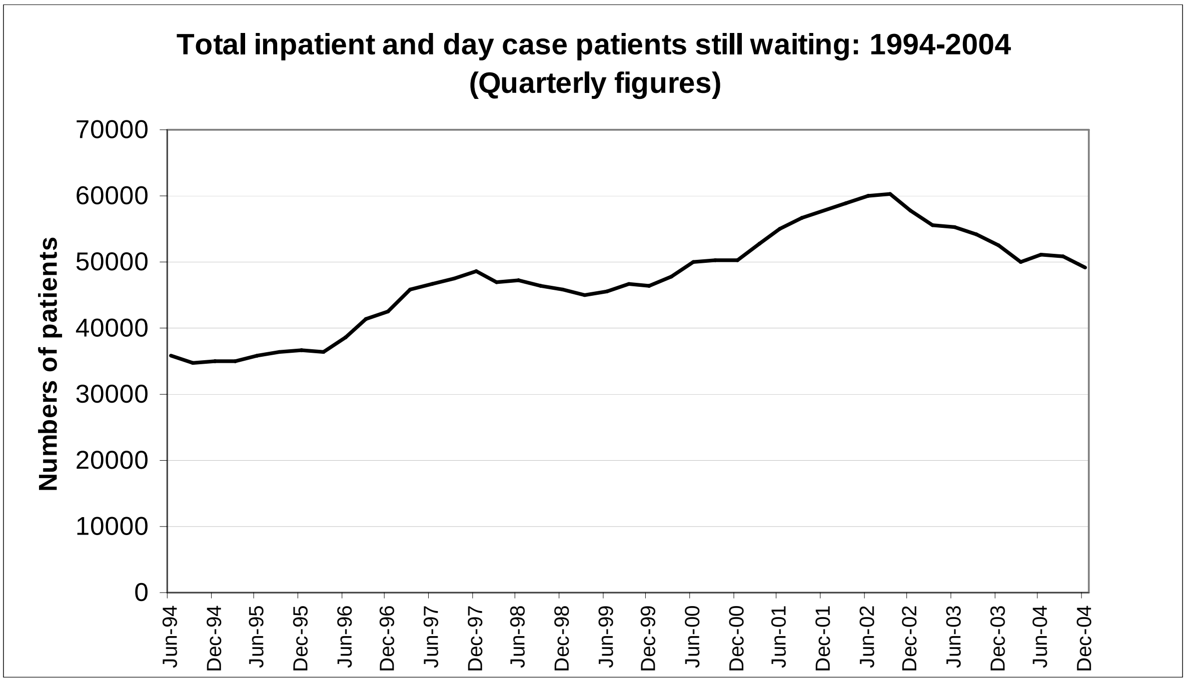


3.6.4 Inpatient and day case waiting

In December 2004, just under 50,000 people in Northern Ireland were waiting to be admitted to hospital for inpatient or day case care (see figure 3.37). The December 2004 reduction brings the total numbers of inpatient and day cases waiting to levels at the turn of the century

This represented 3% of the entire population - 15% more than Wales (2.6%), 36% more than Scotland (2.2%) and 67% more than England (1.8%).

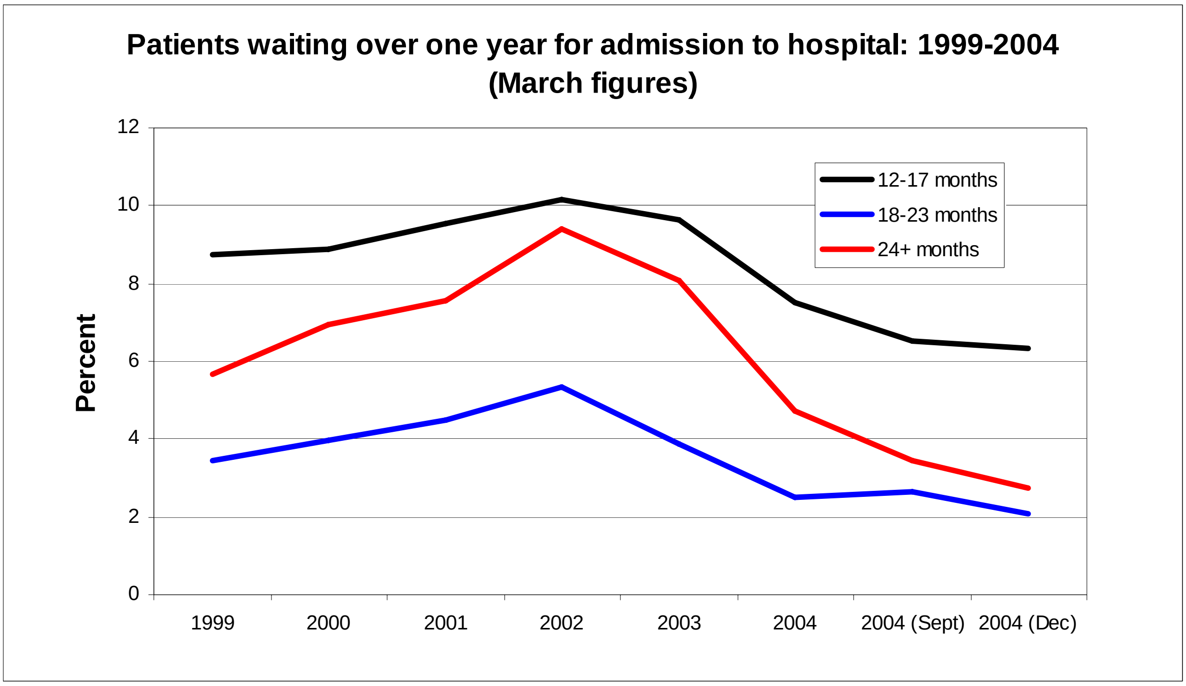
Figure 3.37: The total number of patients still waiting for admission to hospital has started to fall from its peak in 2002, but December figures show a levelling off at around 50,000



But while the total size of the waiting list for hospital admission can make headlines, of real concern to patients is how long they have to wait before admission.

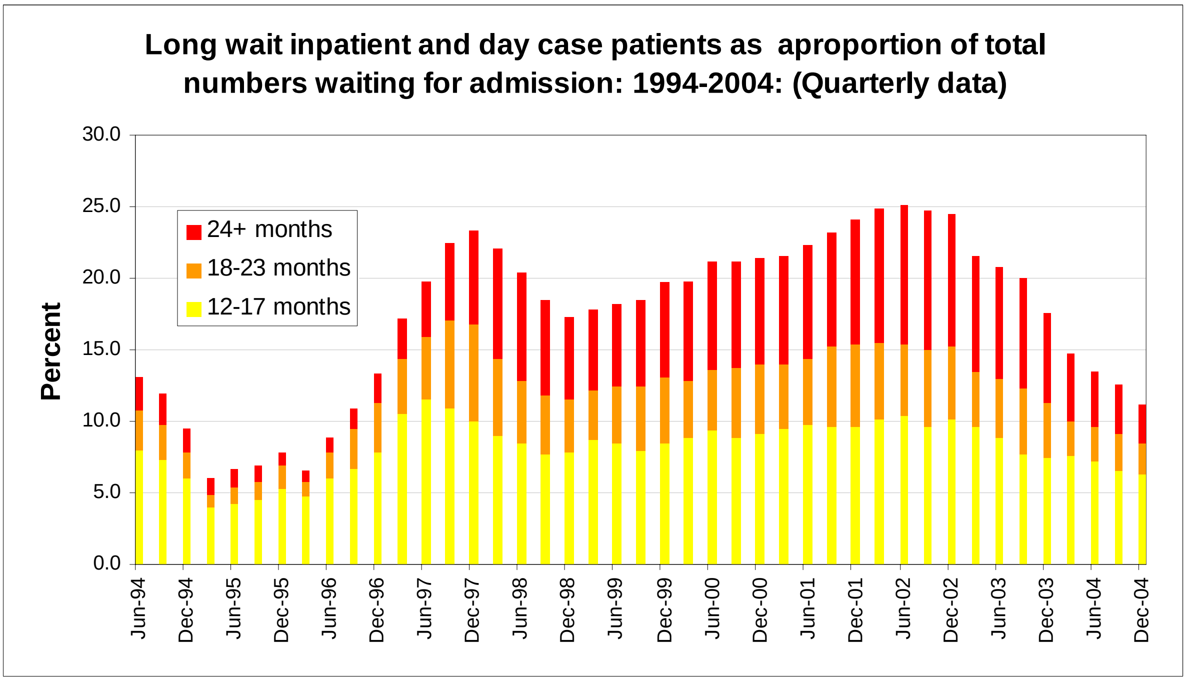
In terms of long waits - of which there is no definition, but over a year, might be a reasonable view of a long wait - there has been some progress over the last two years. Figure 3.38 shows that since March 2002, the numbers of patients waiting over a year have reduced considerably - although the rate of fall has slowed in recent quarters.

Figure 3.38: The numbers of patients still waiting over one year for admission to hospital have, since 2002, fallen to the level in 1999, and in December 2004 the number fell further, to 5,501.



These recent falls suggest that reducing long waits is not an intractable problem. However, looking back further over trends in long waits provides a mixed picture. As figure 3.39 shows, over the last ten years the proportion of the total inpatient list waiting over 12 months, has fluctuated between 6% and nearly 25%. There have been periods of significant reductions in long waits, but also subsequent periods where the proportion (and absolute numbers) have then built up again.

Figure 3.39: Since their peak in 2002, when a third of all inpatients and day cases were still waiting over 9 months for admission to hospital, the proportion of long waits reduced



Such trends raise the question of the sustainability of past attempts to reduce long waits and the effectiveness of actions and strategies to reduce waiting times. We return to these later on and in section 4 which looks at the performance management system.

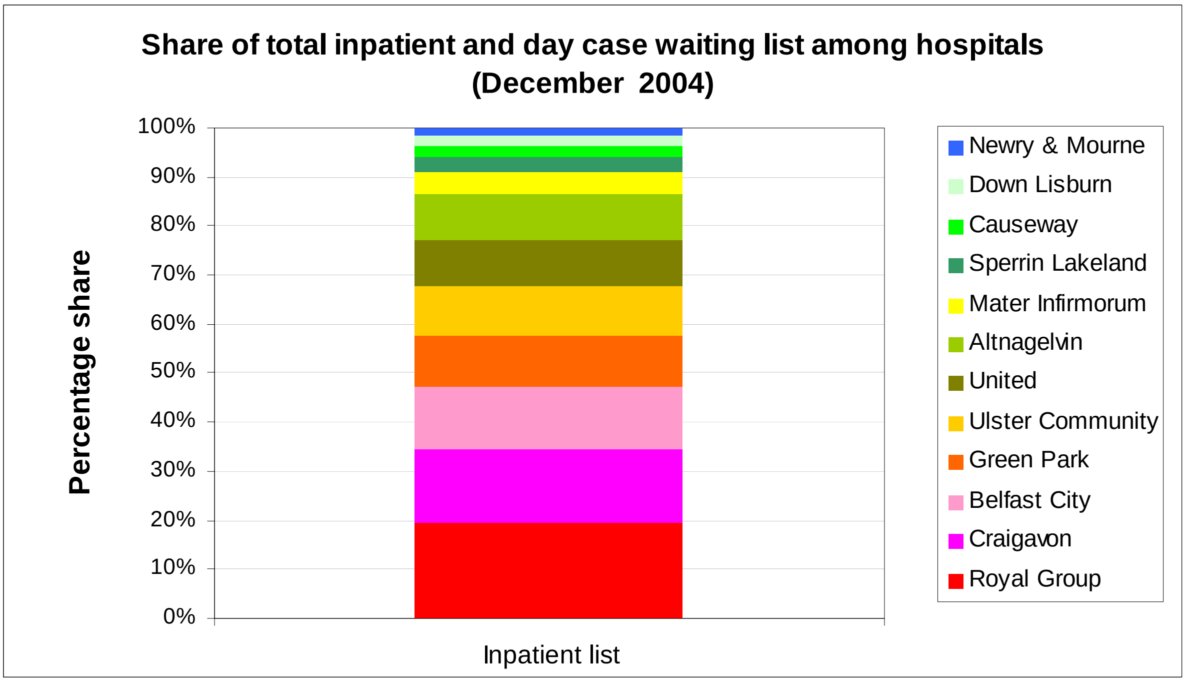
3.6.5 Variations in inpatient and day case waiting times

Apart from variations in waiting times over time, waiting times also vary among specialties, hospitals and in comparison to Wales, Scotland and England.

Variations by hospital

Figure 3.40, for example, shows that nearly 70% of all those on waiting lists are awaiting admission to five hospitals across Northern Ireland.

Figure 3.40: Just three hospitals account for nearly half of the total number of patients still waiting to be admitted to hospital



In part such variations in the share of the total list is explained by differences in the workloads of hospitals. Figure 3.43, for example, shows a relationship between trusts' shares of the total waiting list and their shares of total inpatient and day case activity (for 2003/4). Three hospitals, however, appear to have higher shares of the waiting list than might be expected given their workloads - the Royal Group, Craigavon Area and Green Park.

Figure 3.41: Over a quarter of patients in four hospitals are waiting more than a year for admission to hospital

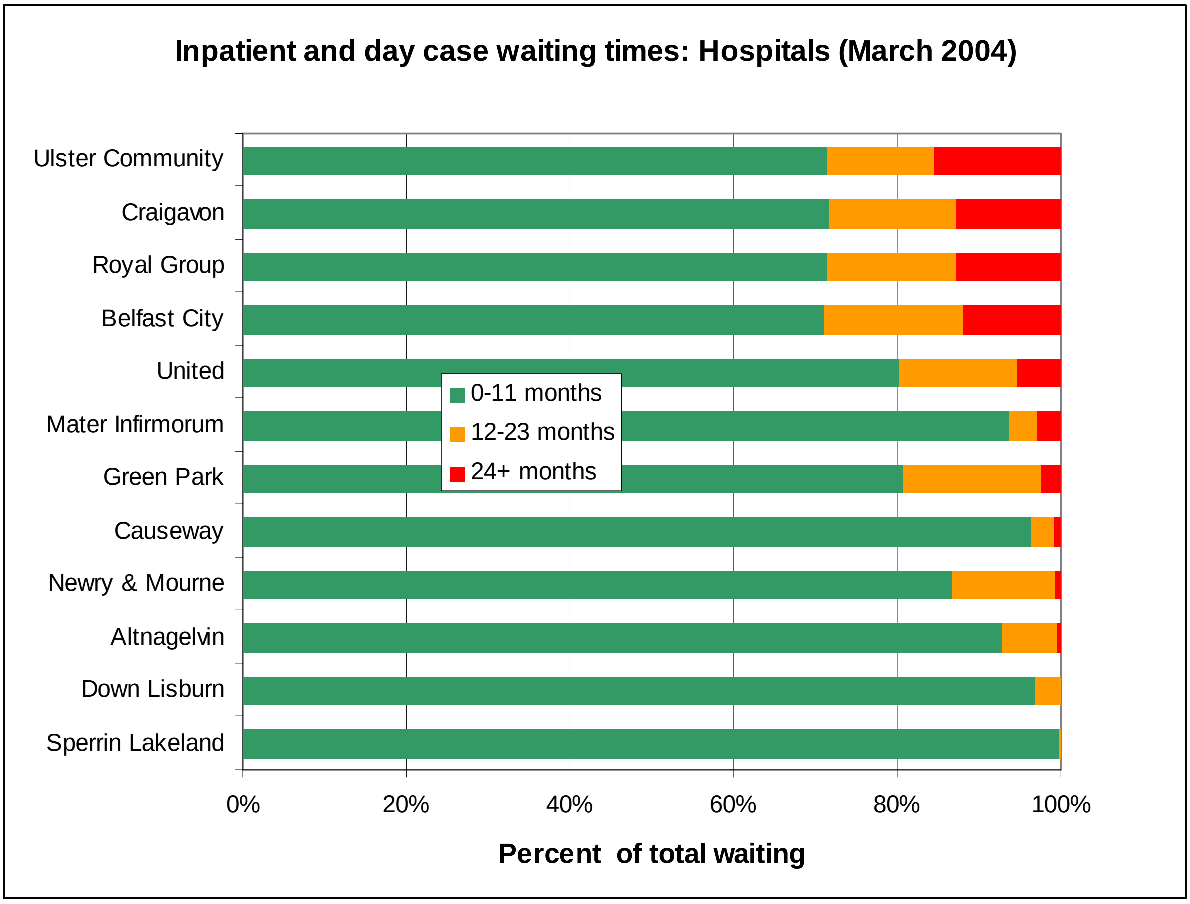
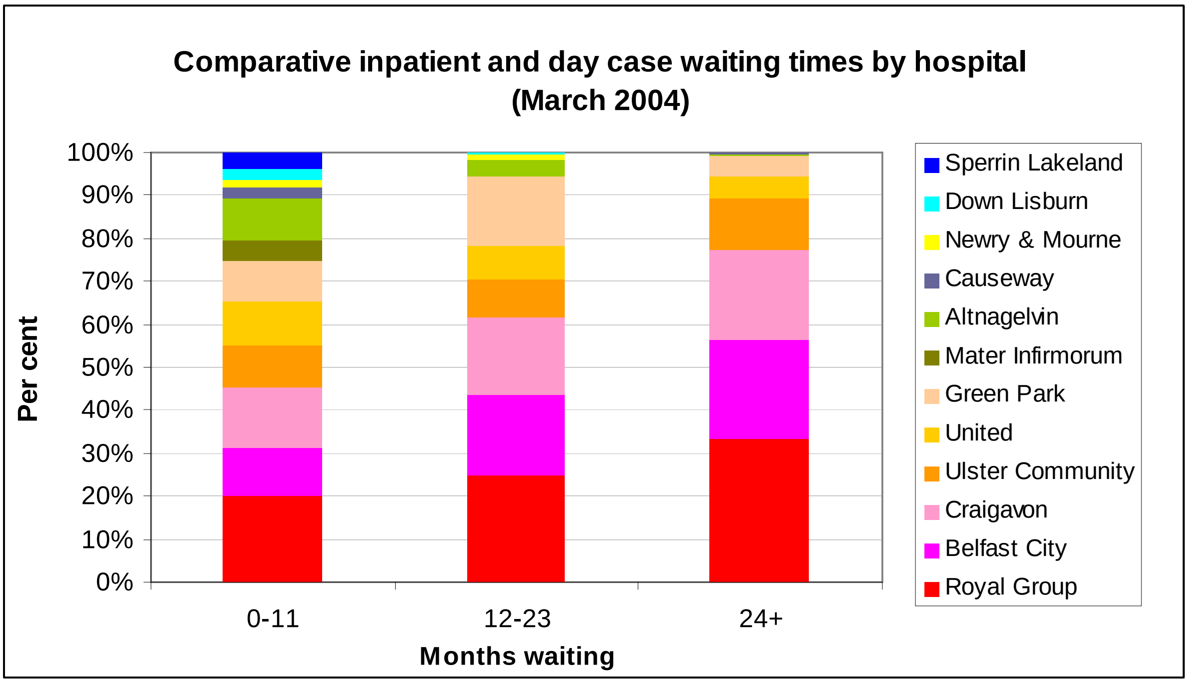


Figure 3.42: Just four hospitals account for nearly 90% of all patients waiting over 2 years for admission to hospital; five hospitals account for nearly 80% of patients waiting 12-23 months…



Variations in waiting times are also evident. And again, while these can in part be explained by differences in the workloads of hospitals, the relationship is not as clear cut as with the size of lists, and further, the same three hospitals - the Royal Group, Craigavon Area and Green Park - are outliers, with a higher share of patients waiting over 12 months than might be expected given their activity levels.

Figure 3.43: Some hospitals have a larger share of the total waiting list than might be expected given their share of total activity

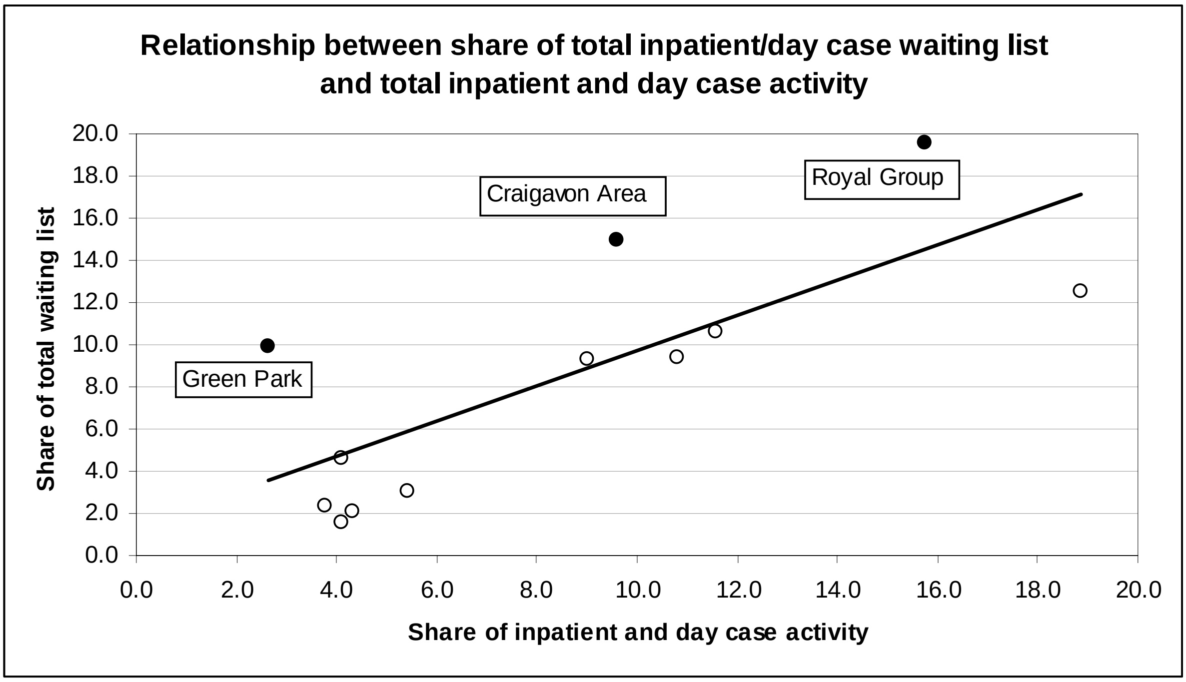
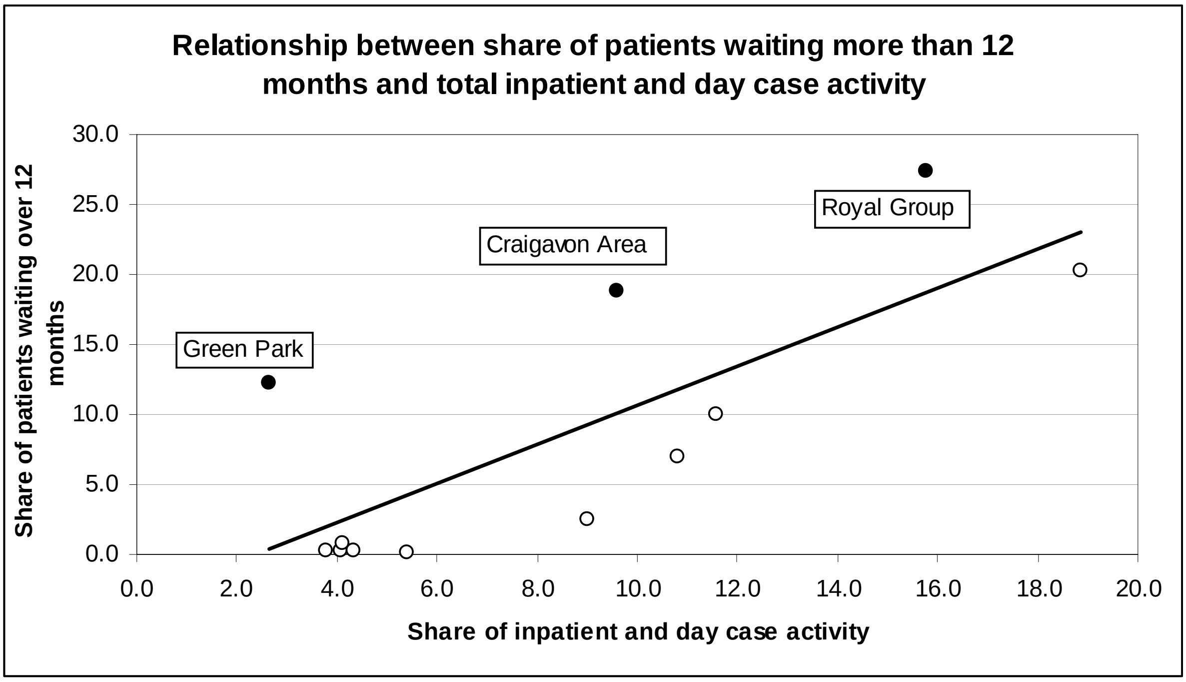
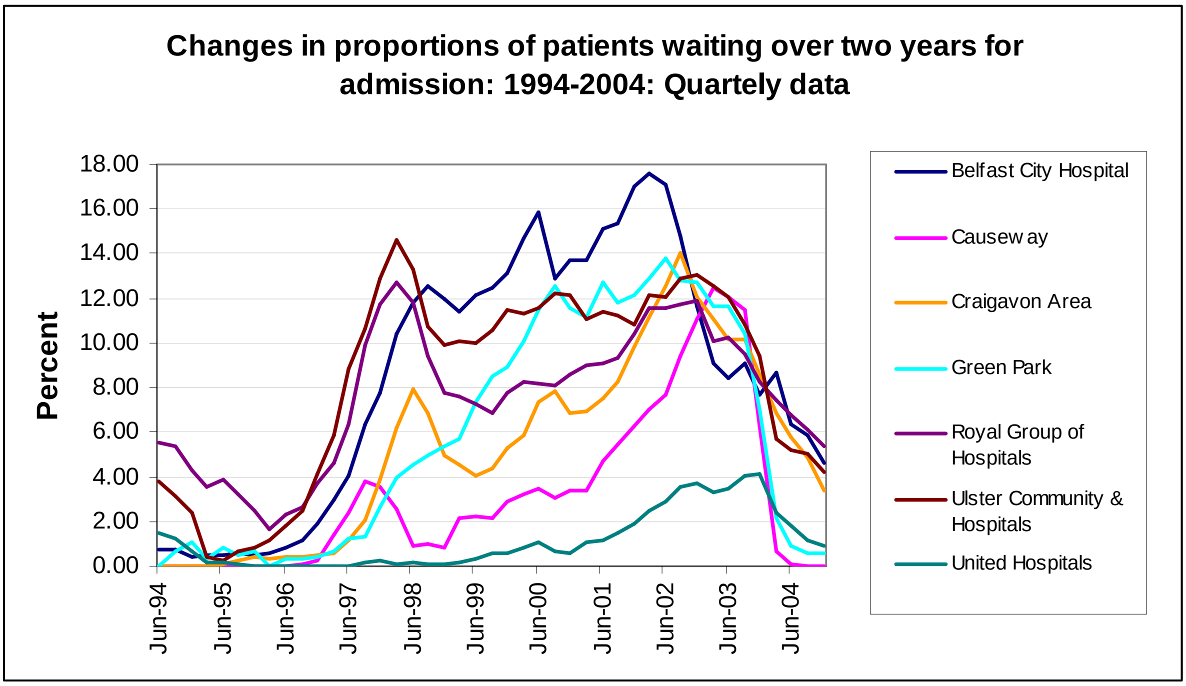


Figure 3.44: Some hospitals have a higher proportion of patients waiting over a year than might be expected given their share of total activity



However, the fact that some hospitals have managed, for example, to virtually eradicate very long waits of over two years while others, with similar proportions waiting over two years in 2002, and although making big reductions over the last two years, have not, suggests that not all the variations in waiting times across hospitals are justified (see figure 3.45).

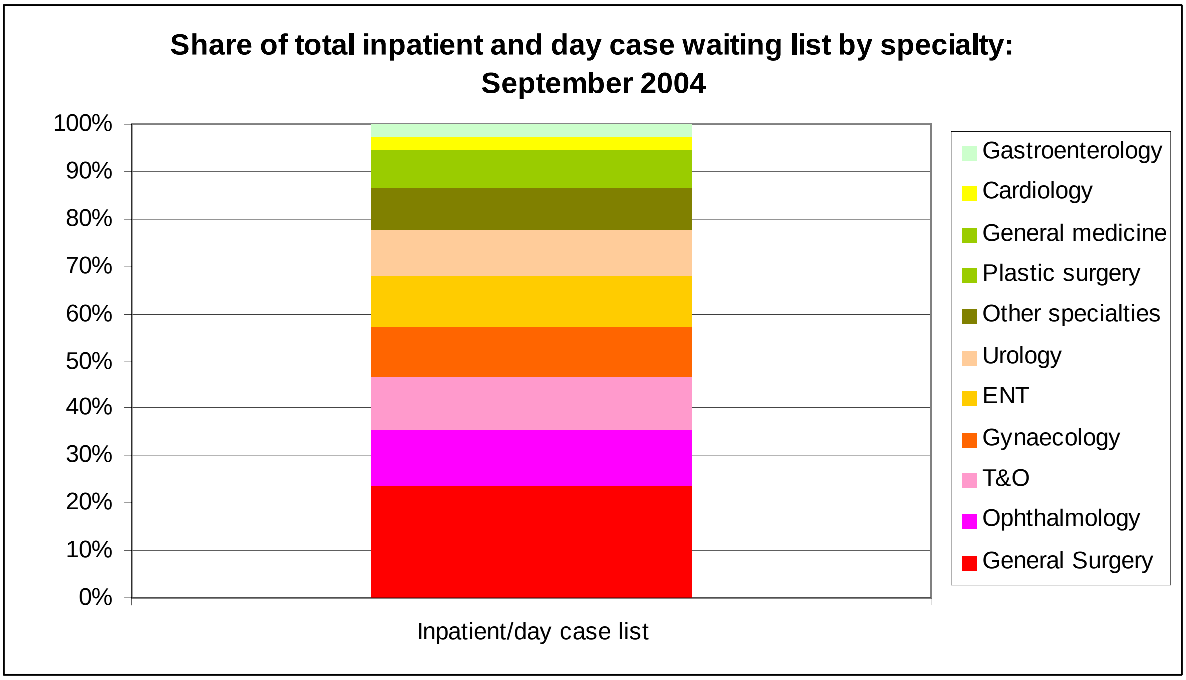
Figure 3.45: Some hospitals have managed to almost eradicate very long waits



Variations by specialty

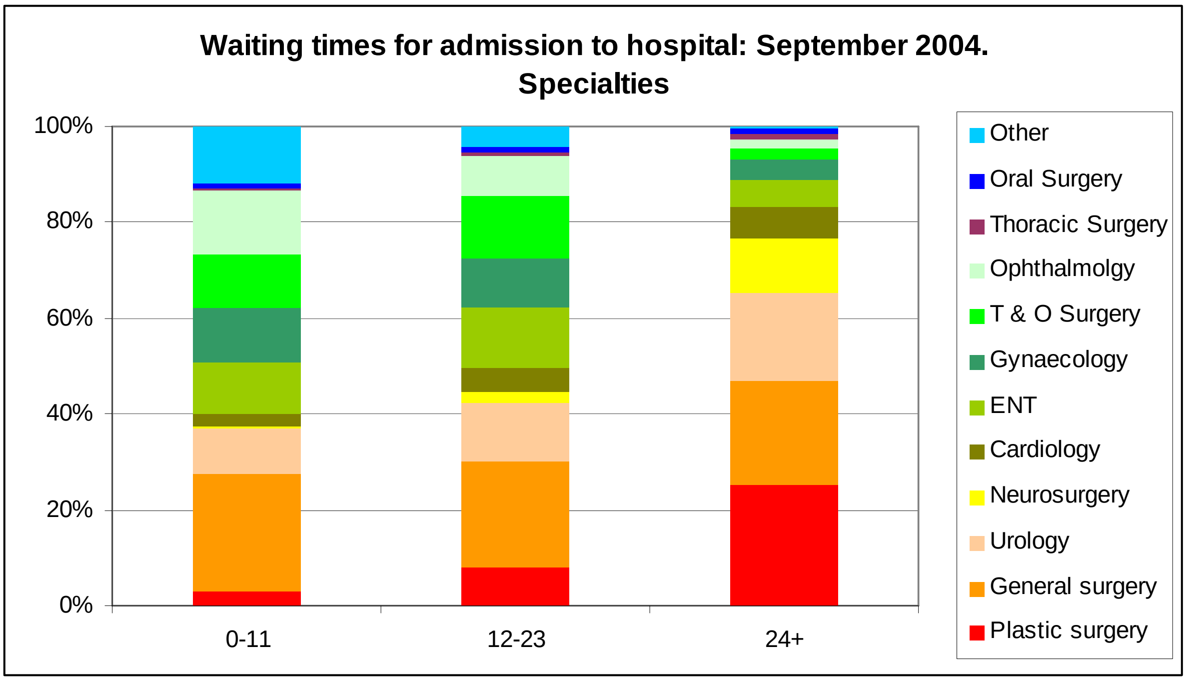
As with outpatient waiting lists and times, there are significant variations across specialties for inpatient and day case waiting lists (see figures 3.46 and 3.47).

Figure 3.46: Just four specialties account for nearly 60% of all p[patients on inpatient/day case waiting lists.



Again, as with outpatient waiting, the bulk of those waiting for admission to hospital are waiting in just a few specialties (general surgery, ophthalmology, trauma and orthopaedics…). And similarly, the majority of those waiting excessive times for admission are also concentrated in a handful of specialties - particularly, plastic surgery, general surgery and urology.

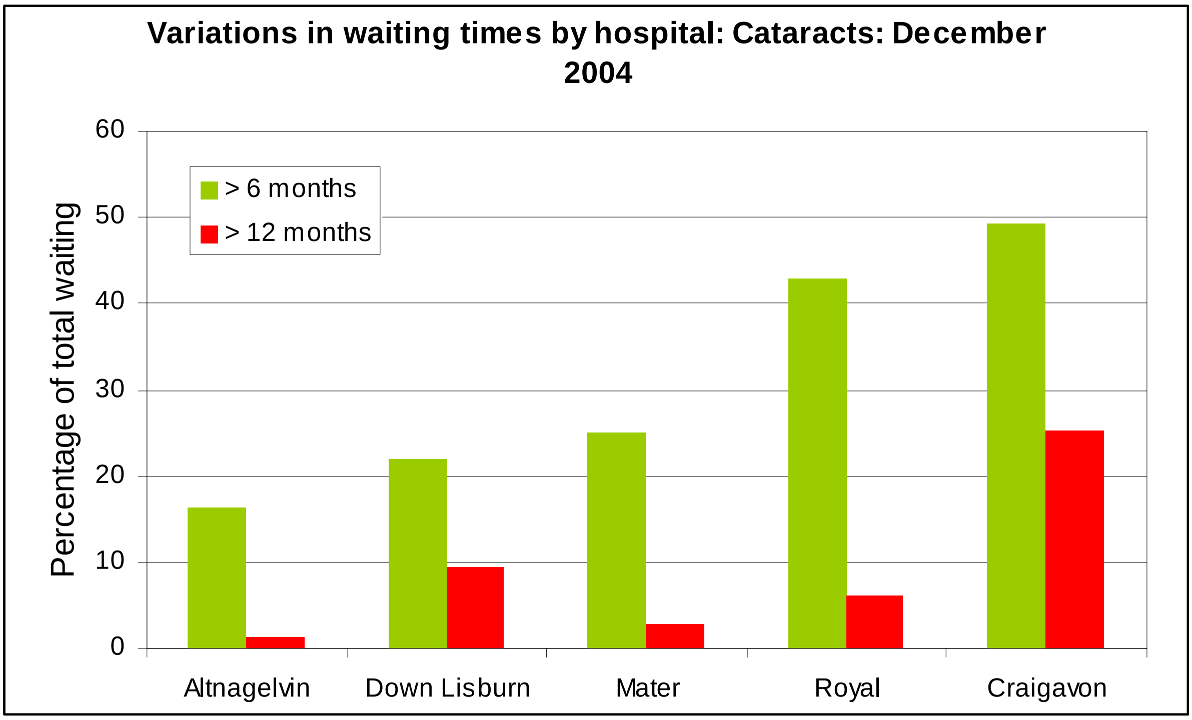
Figure 3.47: Just three specialties account for over 65% of patients waiting over 2 years; six specialties account for 60% of all patients waiting 12-23 months



Moreover, the majority of some specialty lists and waits are concentrated in just a handful of hospitals - sometimes, as in the case of trauma and orthopaedics, just one hospital - Down and Lisburn - accounts for over 82% of the total list. And in the case of ophthalmology, 62% of the total list is accounted for by the Royal.

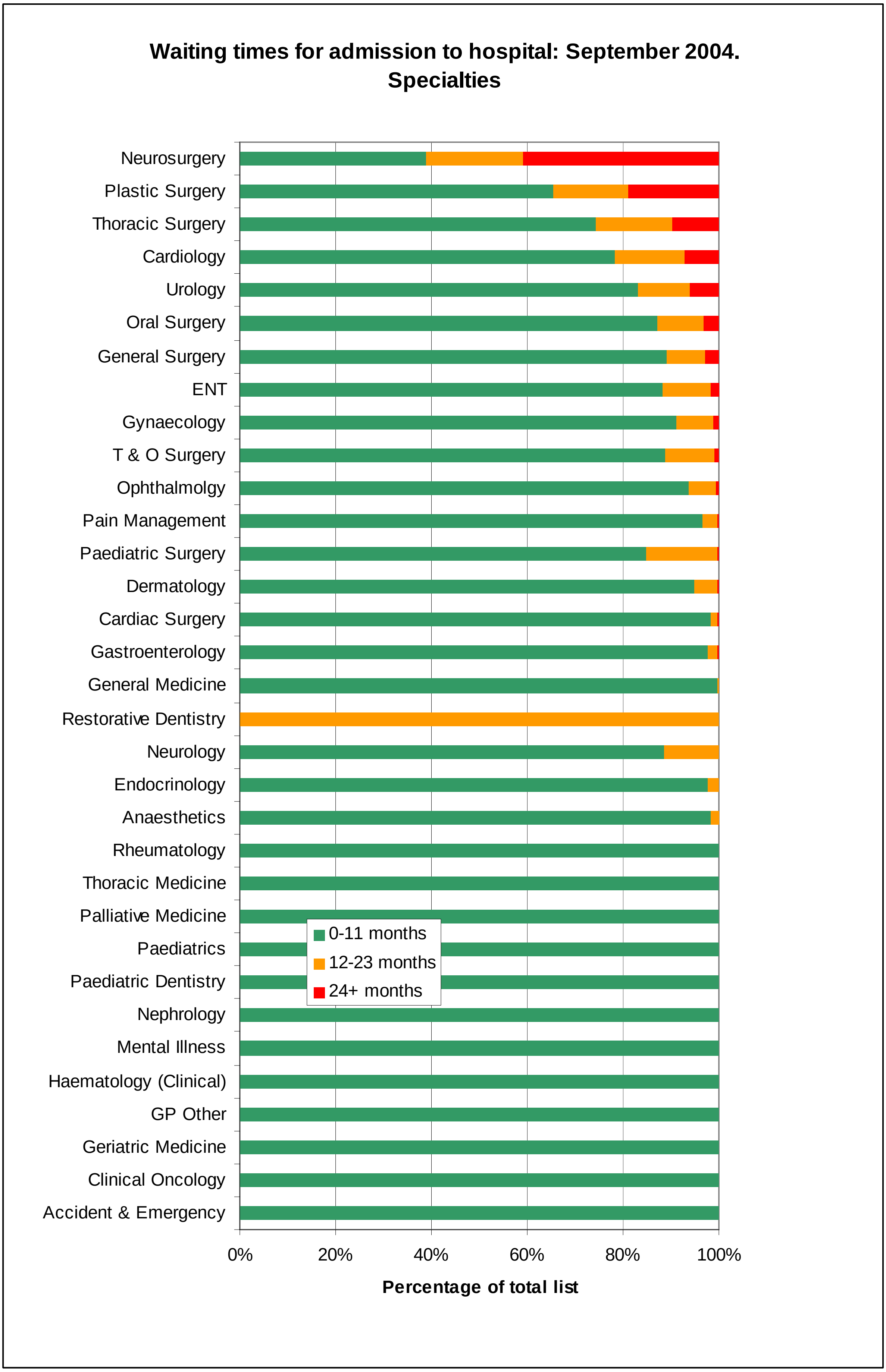
At the level of individual procedures there are also variations in waiting times, as figure 3.48 shows for cataract procedures.

Figure 3.48: Nearly half of all patients waiting for a cataract operation at Craigavon wait over six months; while at Altnagelvin only 16% do so.



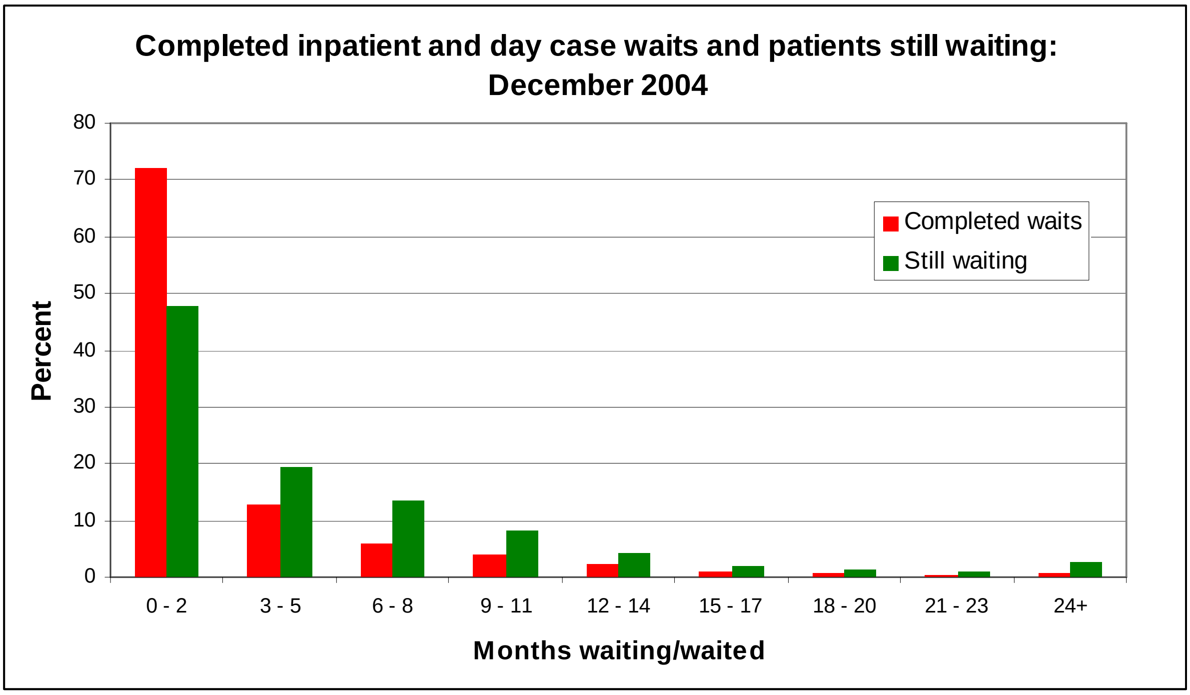
The reasons for very long waits in some specialties will depend on the nature of the specialty, the patients and the nature of the condition to be treated. For example, one reason for the very long waits in plastic surgery is undoubtedly the fact that much of the work carried out in this specialty is non-urgent and patients are rarely in pain.

Figure 3.49: 40% of those waiting for admission to neurosurgery have been waiting over two years.



As with the pattern of outpatient completed waits and those still waiting, patients who are admitted to hospital generally wait less time than those still on the list. In part this is a quirk of the data collection, but it can also be symptomatic of the dynamics of the way lists work in which a group of patients, considered by clinicians to be non-urgent, are bypassed by those deemed to be more urgent; some patients may find it very hard to move up and off the waiting list in this situation.

Figure 3.50: Patients who have been admitted to hospital tend to have waited less time than those still on the list. This is partly due to under 3 month waits being under-recorded by the quarterly census of those still waiting, but may also indicate a 'mortlake' of bypassed patients.



Variations across the UK

There are significant variations in waiting lists and waiting times across the four UK countries. Figure 3.51 shows that Northern Ireland has longer waiting lists per 1000 population and poorer waiting times than Wales, Scotland and England. And figure 3.52 clearly shows the shorter waiting time experience for patients in England and Scotland compared to Northern Ireland and Wales.

Figure 3.51: Compared with the rest of the UK, Northern Ireland has the greatest number of patients per 1000 population still waiting for admission to hospital. It also has the greatest number still waiting over one year for admission per 1000 population

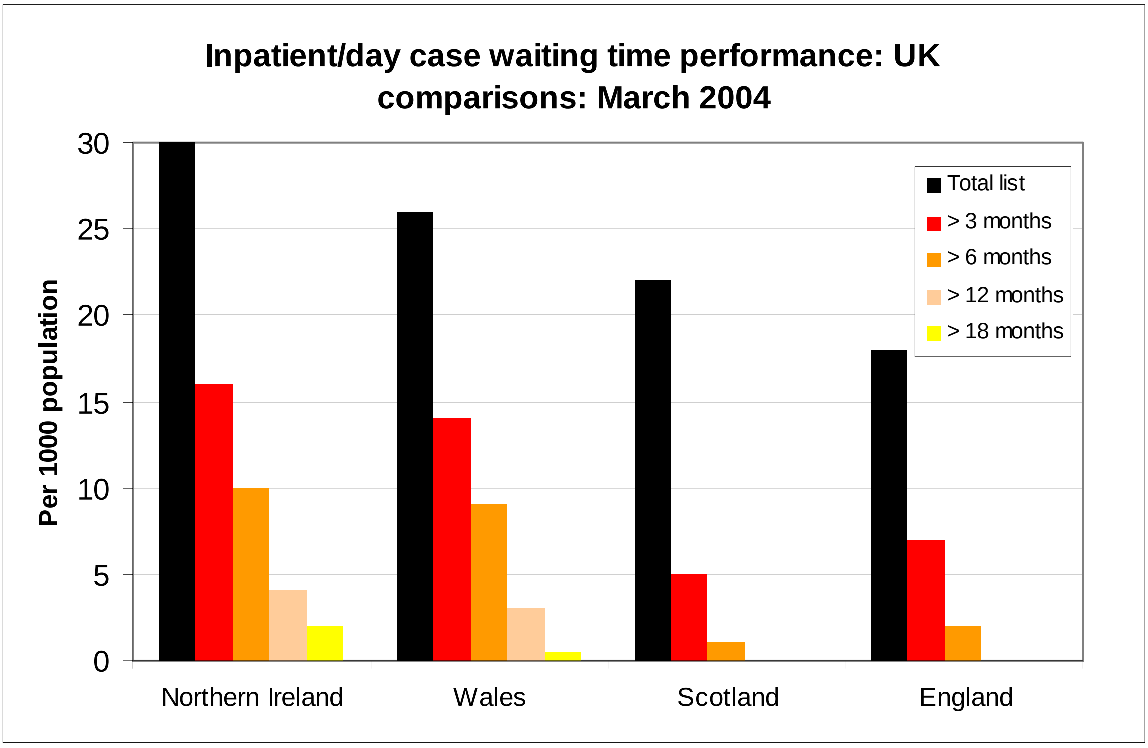
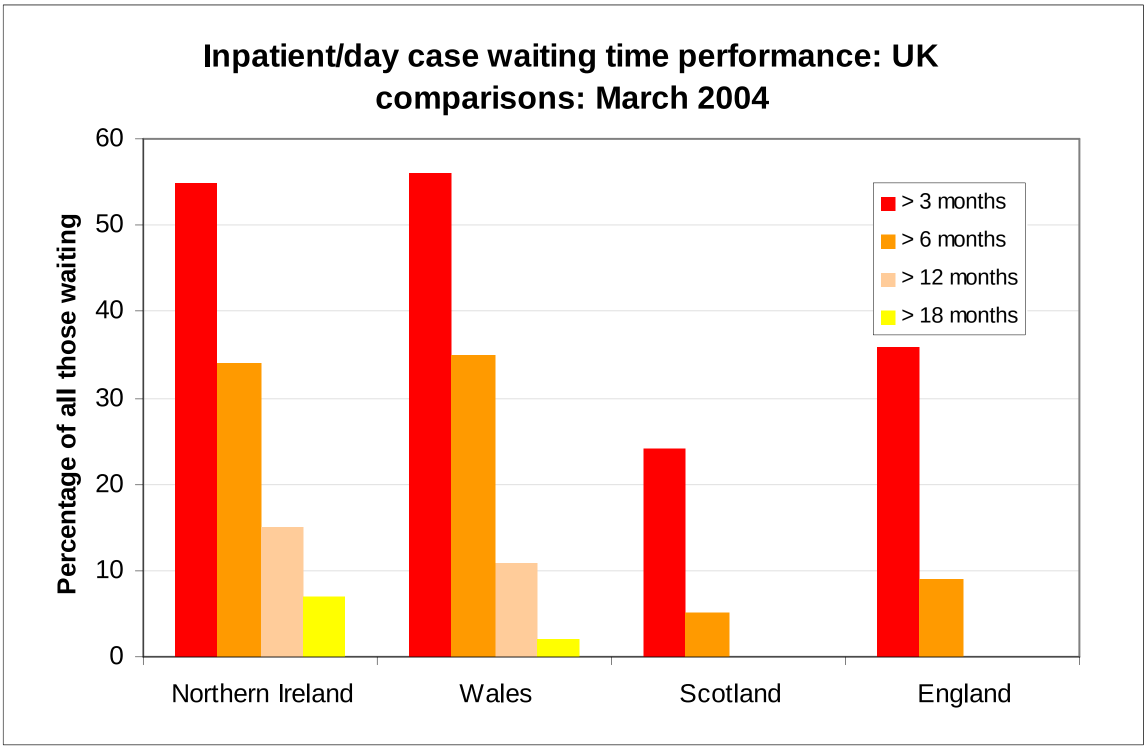
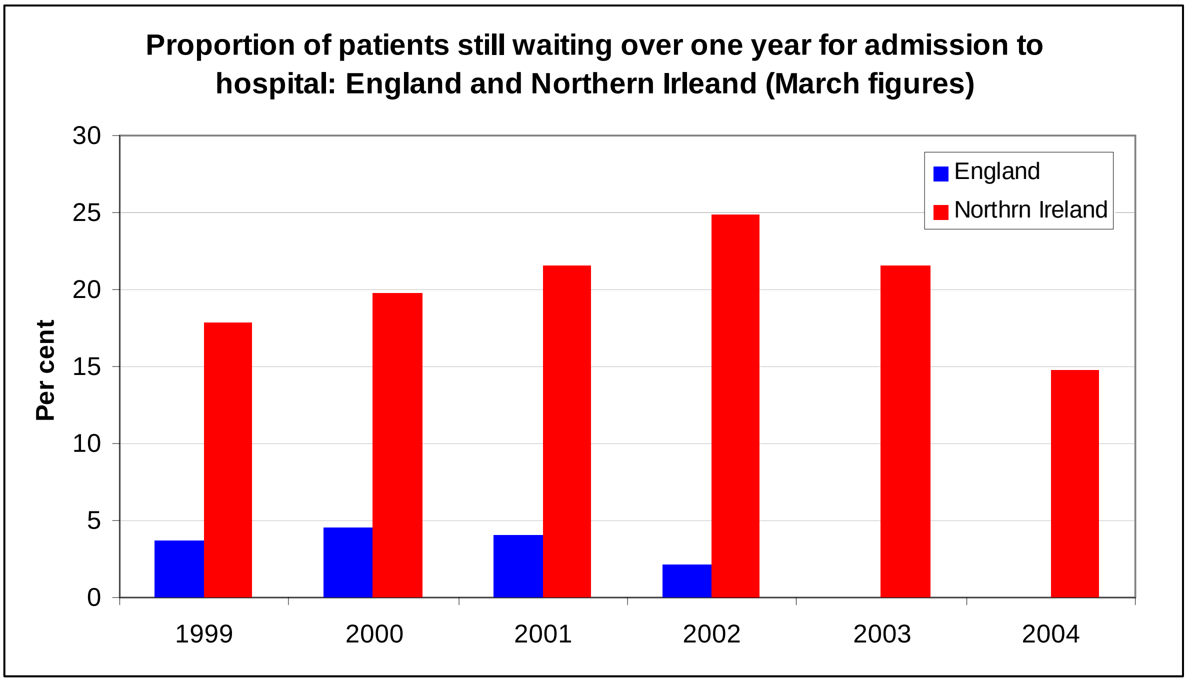


Figure 3.52: Northern Ireland currently has the worst waiting times situation for long waits for admission to hospital of any region of the UK.



The waiting times gap between, for example, Northern Ireland and England, is not a recent phenomenon; figure 3.53 shows that Northern Ireland is lagging someway behind England. Recent falls in the proportion of those waiting over a year are encouraging, but only take Northern Ireland to where England was in 1988 when a similar proportion of patients (15%) waited over a year.

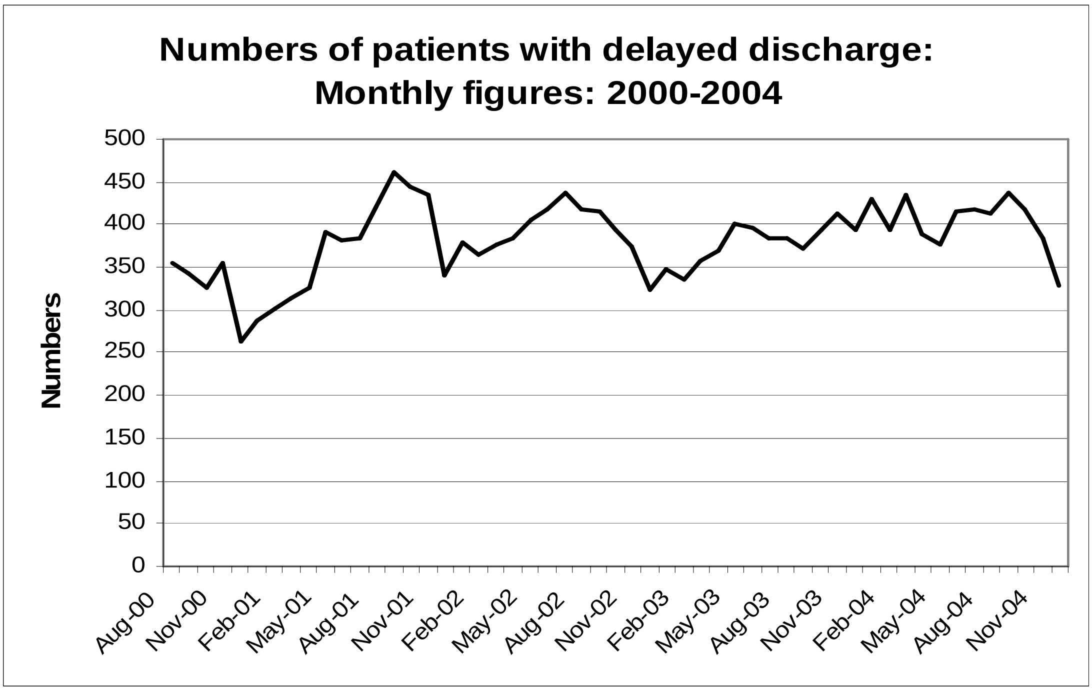
Figure 3.53: Compared with England, over the last six years Northern Ireland have performed poorly in reducing the numbers of patients waiting over one year for admission to hospital.



3.6.6 Waiting for discharge

As noted earlier, waiting occurs in many parts of a health care system. And potentially almost as distressing for patients as waiting to get into hospital, is waiting to get out - to be discharged - after treatment. Delays in discharges from hospital have remained at around 350 to 400 patients in any one month for the last four years (see figure 3.54); this is equivalent to a hospital the size of Altnagelvin Area Hospital occupied with patients (overwhelmingly over 75 years old) simply waiting to go home or on to other nursing or residential home accommodation.

Figure 3.54: Since 2000, the number of delayed discharges has remained around 350 to 400 - tying up 4% of all beds.

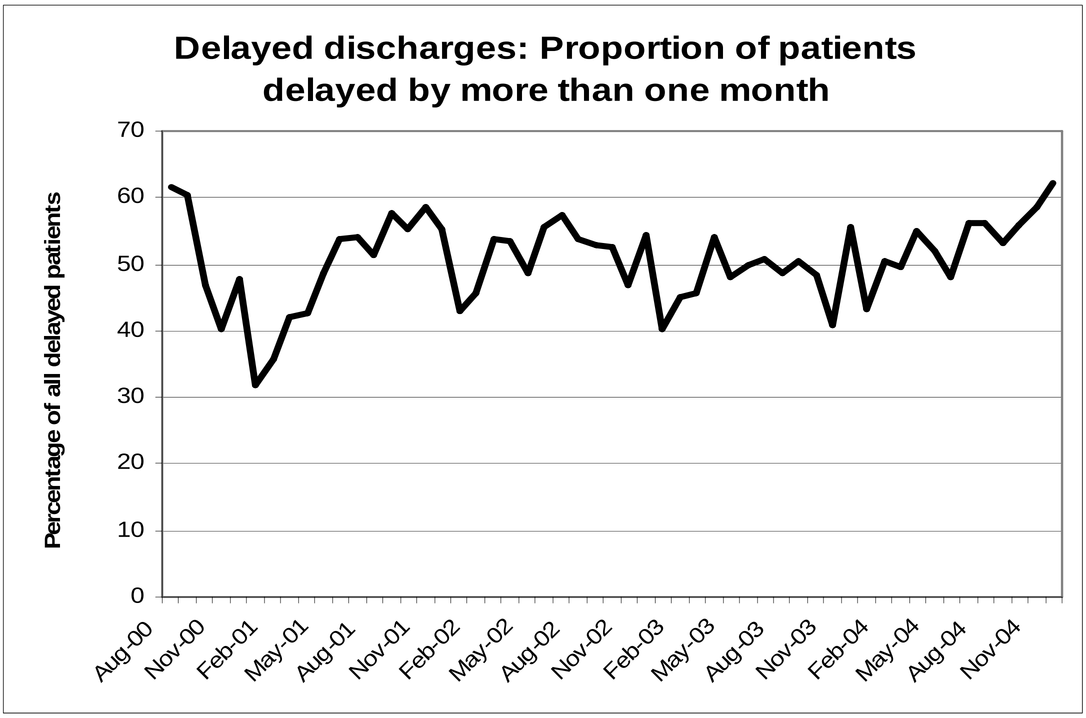


While the proportion of beds tied up with delayed discharges in Northern Ireland - 4% - is lower than in Scotland (6.2%) and Wales (5.1%), it is more than twice as high as in England, where significant reductions have been achieved over the last few years.

For those patients experiencing delays in discharge, waits can be considerable. Currently, as figure 3.55 shows, over 60% of all delayed discharge patients have been waiting over a month to leave hospital; and over a fifth are waiting more than three months, with over 6% waiting over six months.

The reported reasons for delayed discharges are most commonly ‘lack of funding’, waiting for an assessment of needs in hospital, and, the lack of an available and appropriate care package.

Figure 3.55: The proportion of patients delayed in hospital by more than one month has remained at around 50% of all delayed discharges since 2000



3.6.7 Targets to reduce waiting lists and times: a failed strategy?

It is clear that waiting times in most parts of the Northern Irish health system are, despite some improvements recently, very long - especially in comparison with England.

A significant minority of patients wait more than two years just to get a first outpatient appointment. A proportion of these patients who are then placed on the inpatient/day case waiting list will then go on to wait a further two or more years before being admitted to hospital. In total, some patients will have waited four or more years from the time they were referred by their GP until they get a bed in hospital - an intolerable length of time to have to wait for treatment. And, somewhat ironically, not only can it be difficult for some patients to enter hospital, it can also be difficult to exit; every year hundreds of patients find themselves unable to leave hospital for many weeks or even months due to discharge problems of one sort or another.

Dealing with the problem of (unnecessary and excessive) waiting in different parts of the health and social care system is not, as other countries have found, easy to do. One common approach has been to set targets for reductions in waiting lists and waiting times - a strategy which arguably has been the key factor in driving down waiting times in England over the last few years.

In Northern Ireland, targets, dealing with various aspects of waiting, have been in place (and promulgated by the Department’s annual Priorities for Action documents) since the early 1990s (following the introduction of the Patient’s Charter). However, as Box 3.4 details, since 1997, very few targets have been achieved. Moreover, as can also be seen from Box 3.4, target setting has been somewhat erratic, with little apparent long term goals and intermediate milestones set, noticeable gaps (for example, no targets for reducing outpatient waiting times) and with many targets only appearing once over the last seven years despite not being achieved.

Box 3.4: Waiting time targets: 1997/8 to 2005/6

Centrally set targets for any aspect of waiting in the Northern Irish health and social care system have been abstracted from the Department of Health's annual Priorities for Action documents.

1. 2004/05

Target	Date to be achieved	Outcome?
No inpatient/day case to be waiting >6 months	2006/7 or 2007/8	This is a general indication of the timescale in which such a reduction should be reached. It is not, at present, considered by the DHSPSS to be a target as such.
95% of patients requiring hospital inpatient or day case treatment to be admitted within 12 months of being placed on a waiting list	March 2005	**Not on target?**: By December 2004, 11.1% still waiting >12 months. However, of those *admitted* in the quarter, 95% had waited 12 months or less.
Other than in exceptional circumstances, no patient to be waiting for inpatient or day case treatment >18 months	March 2005	**Target unlikely to be achieved**: By December 2004, 4.8% still waiting >18 months
No patient to be waiting for inpatient or day case treatment >15 months	March 2006	**On target?**: By December 2004, 6.9% still waiting >15 months
Number of delayed discharge days to be reduced by 10% compared to 2003/04 levels	March 2005	**Not on target:** Between March and December 2004 there were a total of 80,290 delayed discharge days, against a target reduction of 90,878 by March 2005.
Number patients waiting >2hours in A&E between a decision to admit and admission to a ward to be reduced by one third of 2003/4 levels	March 2005	**Not on target:** Between March and December 2004, 24,087 patients had waited more than two hours in A&E between a clinician's decision to admit and admission to a ward, against a target of 20,568 by March 2005.
Improve access to primary care services by ensuring that 90% of patients who request a clinical appointment (for other than emergencies) will be able to see a General Practitioner or an appropriate primary care	March 2005	**On Target** Boards anticipate meeting this target although the SHSSB has indicated some slippage will occur.

professional within the practice or provided by the practice within 2 working days		
85% of all people who are medically fit for discharge from hospital but who require access to community support to facilitate their discharge should wait no more than 8 weeks for such services to be provided	March 2005	**Unlikely to be Achieved** At December 2004, this standard was being met in the WHSSB area only. Elsewhere performance ranged from 66% to 73%.
To have made demonstrable progress towards achieving the strategic target of a 75% response rate within 8 minutes across all Board areas by 2007	March 2005	**On Target** Systems will not be place to enable the target to be measured until March 2006 but Boards record progress on track for delivery by 2007.

2. 2003/04

Target	**Date to be achieved**	**Outcome?**
Numbers of patients waiting longer than 18 months for hospital inpatient or day case treatment to be reduced by 50% from the level at June 2002	March 2004	**Target exceeded:** 61% reduction achieved
Number of patients waiting for hospital inpatient or day case treatment to be reduced by 5% from the level at June 2002	March 2004	**Target exceeded**: 16.7% reduction achieved.

3. 2002/03

Target	**Date to be achieved**	**Outcome?**
Constrain hospital waiting lists to the March 2002 level	March 2003	**Target exceeded**: total numbers fell by 2,767 (4.8%)

4. 2001/02

Target	**Date to be achieved**	**Outcome?**
Reduce waiting lists by a quarter, from 51,000 to 39,000, with a milestone reduction to 48,000 by March 2002	March 2004	**Not achieved:** waiting lists *increased* to 57,000 in March 2002, and were just under 50,000 by March 2004
No patient to be waiting >18 months, with a milestone reduction of 50% in those waiting >18 months by March 2002	March 2003	**Not achieved:** Numbers waiting >18 months and cardiac patients waiting >12months increased by 2,337 (+36%) over March 2001 levels; by March 2003 the number of 'excess waiters' was 6,659, an increase of 229 (+3.6%) over March 2001 levels.
No cardiac patient to be waiting >12 months, with a 50% reduction in those waiting >12 months by March 2002	March 2003	
No patient to wait >48 hours for surgery in fracture clinics	No date set	**Not Achieved.** Work was being addressed

		on a regional basis through the Fracture Crisis Working Group in which Boards participated. DHSPSS state that: "Winter pressures reduced the impact of the additional capacity introduced into the system."
Reduce the number of people waiting for occupational therapy assessments for housing adaptations at April 2001 by 20%	March 2002	**Not achieved.** Northern Board reduced the numbers waiting by 19% and Western Board by 17%.

5. 2000/01

No specific targets set in this year. General exhortation from DHSPSS to maintain downward pressure on waiting lists and ensure that gains made were not lost: By March 2001, waiting lists rose by 16.7%

6. 1999/00

Target	**Date to be achieved**	**Outcome?**
Maximum wait for outpatient appointment no more than 3 months from time of GP referral	2000	**Not achieved**: 77% seen within 3 months
No patient to be waiting longer than 18 months for admission to hospital	2000	**Not achieved**: 96% admitted within 18 months; 12% still waiting > 18 months by March 2000
No cardiac patient to be waiting longer than 12 months for admission to hospital	2000	**Not achieved**: 8% admitted within 12 months;
No patient to wait longer than one month for admission following a cancelled operation	2000	**Not achieved**: 1% not admitted within one month

7. 1998/99

Target	**Date to be achieved**	**Outcome?**
Maximum wait for outpatient appointment no more than 3 months from time of GP referral	1999	**Not achieved:** 80% seen within 3 months
No patient to be waiting longer than 18 months for admission to hospital	1999	**Not achieved**: 95% admitted within 18 months
No cardiac patient to be waiting longer than 12 months for admission to hospital	1999	**Not achieved**: 85% admitted within 12 months
No patient to wait longer than one month for admission following a cancelled operation	1999	**Not achieved**: 0.7% not admitted within one month

8. 1997/98

Target	**Date to be achieved**	**Outcome?**
Maximum wait for outpatient appointment no more than 3 months from time of GP referral	1998	**Not achieved**: 80% seen within 3 months
No patient to be waiting longer	1998	**Not achieved:**

than 18 months for admission to hospital		95% admitted within 18 months
No cardiac patient to be waiting longer than 12 months for admission to hospital	1998	**Not achieved**: 83% admitted within 12 months
No patient to wait longer than one month for admission following a cancelled operation	1998	**Not achieved:** 0.3% not admitted within one month

End of Box 3.4

Despite the apparent lack of success in meeting waiting times targets - the reasons for which are discussed below, and in the next section on the performance management system - there are (recent) examples of successes in tackling the problem of waiting. Box 3.5, for example, summarises some of the approaches taken at local level - often using learning from the Modernisation Agency and experience of the National Patient Access Teams in England in reducing waiting times.

Box 3.5: Examples of success in tackling waiting lists and times in Northern Ireland

The following examples of success in reducing waiting times are taken from *Tried, Tested, Shared 2: Summaries from the Service Improvement projects 2003-04* (DHSSPS, 2004).

The Service Improvement Unit was set up in 2003 and aimed to improve patient and client access '…by engaging multidisciplinary teams in redesign to reduce waits and delays..'. This bottom up, micro approach has helped many trusts improve their waiting times performance.

Causeway Trust managed to completely eradicate over 12 month waiters in just eleven months through a combination of protecting elective beds from emergency use, regular validation of lists, eradicating bottlenecks along the patient pathway, use of a points system to forecast necessary theatre capacity and development of a common general surgery waiting list.

Foyle Trust reduced the waiting time for a first outpatient appointment for its family planning services from 18 weeks to 4 weeks, reduced the average wait within clinics from 85 to 30 minutes and cut its DNA rate by introducing a computerised booking system, providing one contact telephone number for patients, sending out reminders for appointments, introducing nurse-led clinics and extending clinic opening hours.

Craigavon and Banbridge Trust reduced DNAs from 22% to 10% and cut the longest wait for a new assessment from four months to two weeks for its Continence Clinic by validating lists, introducing a partial booking system and generally redesigning clinic structures.

A common outcome of these and many other initiatives has not just been the reduction in waiting times and lists, but improved staff morale and motivation, higher patient satisfaction, improved information systems, a greater understanding of the 'whole system' and how services interlink and the need to monitor performance on an ongoing basis.

3.6.8 Solutions to reducing waiting times?

One, understandable, reason for the lack of success in achieving centrally-determined targets could be that the targets set have been too ambitious. However, as the National Audit Office for Wales noted in its recent report on waiting times in

Wales, in comparison with England, Northern Ireland (and Wales) have historically set rather unambitious targets[70] .

While it has been put to the Review that lack of funding was a key reason for lack of progress in reducing waiting times, this view was contradicted by some senior trust managers and by most of the general practitioners to whom we talked. From our survey of trust chief executives, *lack of funding* was, on average not the main barrier to meeting waiting time targets. In addition, as table 3.4 shows, other barriers were often rated as more important within trusts.

Table 3.4[(a)]: Survey of trust chief executives: 'What are the main barriers to achieving waiting time targets?'

TRUST>	A	B	C	D	E	F	G	H	I	J	K	L	M	N	Average score (d)
Staff vacancies	3	2	3	2	2	1	2	2	2	4	3	2	2	2	2.3
Levels of urgent, but non-emergency work	1	3	4	2	2	3	2	2	3	2	1	3	4	3	2.5
A lack of funding	(b)	3	2	1	3	3	2	(c)	3	4	1	3	3	2	2.5
Higher than expected emergency admissions	1	1	3	4	4	3	4	2	3	2	na	4	5	3	3.0
Insufficient beds	4	1	3	4	4	2	4	2	1	2	na	3	5	4	3.0
An increase in GP referrals	1	3	3	1	4	2	3	3	3	2	3	5	5	2	3.1
Winter pressures	2	2	3	4	3	3	4	2	2	2	5	4	5	3	3.1
Delayed transfers of care	2	1	4	4	4	4	3	3	1	2	na	3	5	5	3.2
Shortage of theatres	3	1	4	3	3	4	4	3	2	2	na	4	4	5	3.2
Unrealistic targets	4	2	2	2	4	3	5	2	4	4	na	3	3	5	3.3
Skills shortage	4	2	3	4	1	5	3	5	4	4	3	5	5	1	3.5
Treating private patients	4	5	5	5	5	5	5	5	5	5	na	5	5	4	4.9

a Rating 1=extremely significant, 2=very significant, 3=significant, 4=slightly significant, 5=not significant at all.
b No score given: 'Varies by specialty'
c No score given: 'Recurring funds a problem'
d Average= sum of scores divided by number of trusts

A more important reason for the apparent failure of the target setting regime in Northern Ireland, and a key theme in the next section on the performance management system, was and remains the lack, as far as this Review could discern, of a consistent commitment throughout the health and social care system to the objective of reducing waiting times, and in addition, the lack of any system of incentives - rewards and sanctions at organisational or individual levels - absolutely necessary in order to drive efforts to meet targets.

Overall, the conclusion of this Review with regard to the issue of waiting is that evidence exists - for example, variations in waiting times across hospitals in Northern Ireland, examples of significant reductions in waiting times in some hospitals and the example of historic reductions in waiting times in England - that excessive waiting is

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[70] See for example Figure 7 in Report by the National Audit Office Wales, NHS Waiting Times in Wales Volume 1- The Scale of the Problem.

not inevitable, nor an intractable problem given the level of financial inputs to the system.

Broadly, solutions to the problem require a ‘whole systems’ perspective, acknowledging that answers to the problem will involve, for example, not just the elective care system, but all parts of a hospital as well as the wider health economy. In addition, solutions necessarily need to adopt the viewpoint of the patient, coupled with a consistent commitment to solving the problem - from managers, clinicians and others concerned with patients’ welfare.

In practice, tackling excessive waiting will involve most if not all of the following:

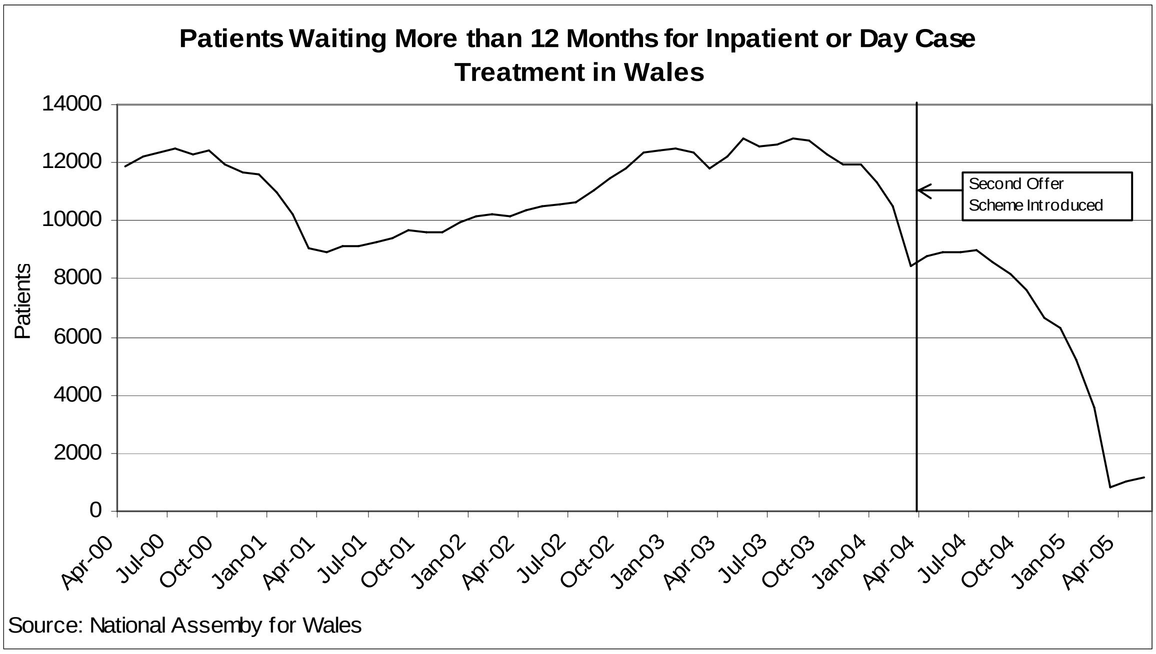
- Efficient use of key resources (theatres, beds, LOS, TOI etc)
- Weekly monitoring of lists by chief executives
- Continual validation of lists
- Treat-in-turn, together with consistent urgency prioritisation
- Clear bottlenecks (e.g. bed blocking, ringfence elective beds)
- Set targets coupled with incentives/sanctions (for individuals and organisations)
- Manage the entire patient pathway - from GP to outpatient to diagnostic services to waiting list to admission to discharge.
- Publish performance data (by hospital, specialty and clinical team).
- Reduce variations through patient choice
- Contain and if possible reduce, other demands on the hospital system - especially accident and emergency attendances and emergency admissions.

Recommendation 12: Adopt multi-pronged long term strategy to reducing waiting times, including long term targets (with milestones) backed by strong incentives.

A series of initiatives have recently been announced in relation to both inpatient and outpatient waiting lists following the work of Dr Martin Connor and colleagues at the Greater Manchester Strategic Health Authority. For those on inpatient waiting lists a ‘Second Offer’ system will be introduced similar to that introduced in Wales in 2004. Under this system, when a trust fails to treat patients within agreed time thresholds, they are offered treatment elsewhere and the original trust has to pay for the treatment in full. The corollary is that patient who refuse a reasonable second offer of treatment will be taken off the waiting list and referred back to their GP.

Figure 3.56 below shows that the Second Offer scheme does appear to have been successful in reducing the numbers on inpatient waiting lists in Wales. However, in their January 2005 report on waiting times, the National Audit Office of Wales raised a number of concerns with the scheme in terms of the impact on financial viability of trusts, disputes as to is responsible for delays in treatment as well as the reluctance of patients to travel.

Figure 3.56: The number of persons in Wales waiting more than 12 months for inpatient or day case treatment has fallen by 87% since April 2004[71].



Source: National Assemby for Wales

The major concern of the Welsh Audit Office, however, was that the scheme did not constitute a clear and coherent overall strategy because it did not address the issue of outpatient waiting and may make the problem worse. In Northern Ireland, this is being addressed by improvements in the management of primary care. Instead of being sent directly to a consultant, non-urgent referrals will be passed to a central assessment service which will determine the most appropriate next stage of treatment. Whilst this scheme has the clear potential to reduce the burden on hospital consultants, this depends on the extent to which consultants are willing to devolve some of their responsibilities to others**.** In addition, this raises questions as to why GPs have been unable to manage demand effectively to date.

Overall, this Review welcomes the adoption of a more robust approach towards tackling the waiting list problem in Northern Ireland hospitals. However, as has been highlighted by the work in Wales, the detail of how the schemes will be implemented is crucial. In particular, care should be taken that the cost of providing an alternative source of treatment is not excessive and that the addition of, in essence, a triage tier to the referral process does not simply create increased bureaucracy .

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[71] This includes those who declined a second offer-719 in May 2005

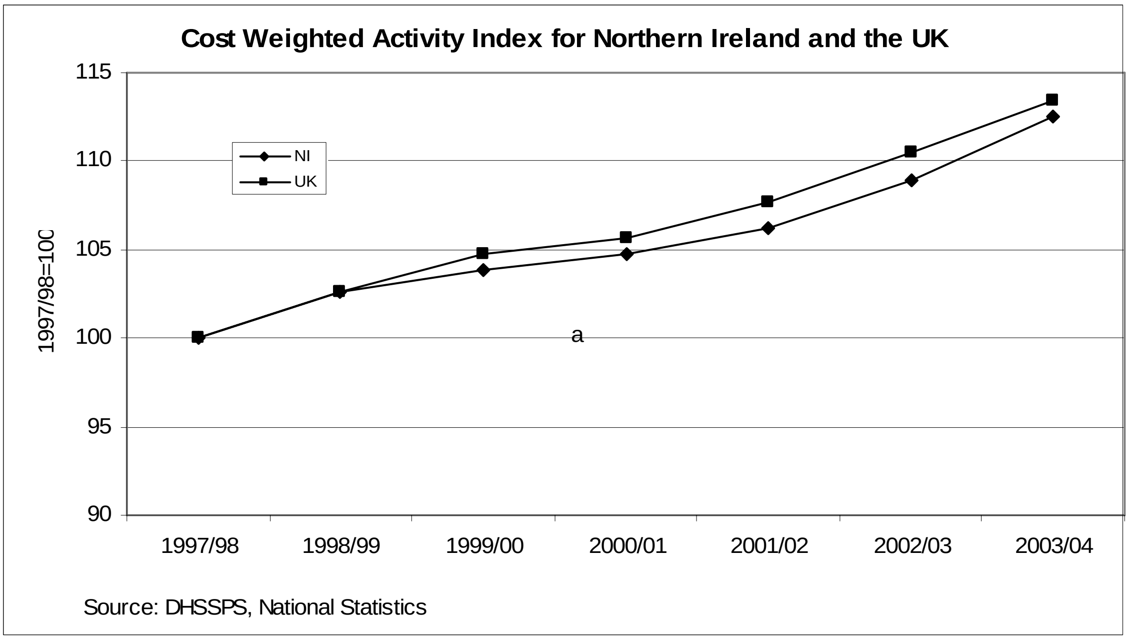
3.7 Efficiency and productivity

In common with most public services it is difficult to determine precisely the extent to which resources have been used efficiently in the health & social care sector. Although the inputs to the system are relatively easy to capture and measure (money, staff etc), the outputs present a more difficult task. For example, whilst population health measures such as age standardised mortality rates are often used as output indicators they are imperfect measures of health system performance as they reflect a range of determinants other than the effects of health and social care services, and often over individuals' entire lifetimes. Moreover, while such measures may capture one of the dimensions of health (in this case, death), other dimensions (quality of life) are just as important.

Unfortunately, health and social care systems do not routinely measure patients' and clients' quality of life, and, coupled with the attribution problem when using measures such as SMRs, traditionally, measures of efficiency have tended to rely on ratios of inputs (money) to outputs - usually measured in terms of activity (patients treated, operations performed etc).

Composite measures of health service activity (adding together different types of activity using share of expenditure as weights (cost weighted activity index - CWAI) divided by changes in real financial resources (the cost weighted efficiency index - CWEI) have been used by the English NHS to capture, in broad terms, the efficiency with which the NHS converts inputs into outputs. However, such measures are, as we note, imperfect (see Box 3.6).

Figure 3.57: The Cost Weighted Activity Index (CWAI) of Healthcare Services increased by 12.5% in Northern Ireland between 1997/98 and 2003/04 compared to 13.4% in England.

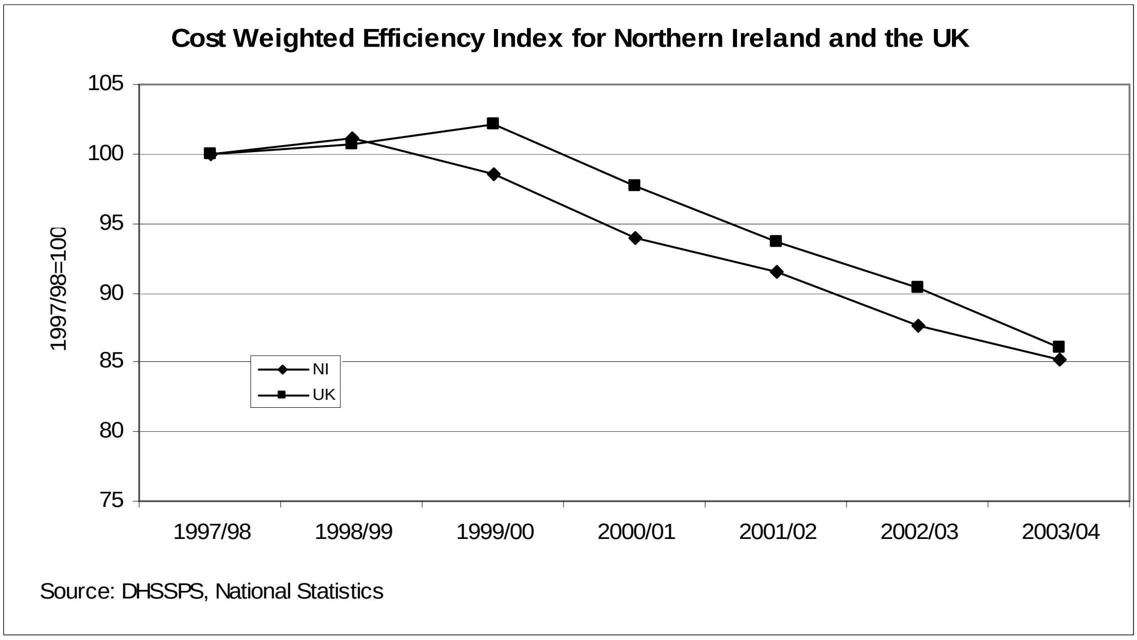


Source: DHSSPS, National Statistics

For illustrative purposes, figure 3.57 compares the increase in health service activity between Northern Ireland and the UK as a whole in terms of the CWAI. The CWAI includes hospital activity (e.g. inpatients, day cases), community activity (e.g. health visiting and district nursing) and family health services (e.g. GP consultations and prescribing) weighted by their shares of total spending. It can be seen that on this measure, activity has risen at a slightly slower rate in Northern Ireland than England between 1997/98 and 2003/04. However, looking at the underlying data in more detail highlights the weaknesses of the indicator. In particular, the greatest contributions to the growth in activity in Northern Ireland come from inpatients and day case activity and GP prescribing activity[72]. In respect of the former, the main growth is mainly attributable to growth in day case activity, which, as these are on average less expensive than inpatient care, in the context of a constant weight suggests that growth is overstated. In addition, GP prescribing in Northern Ireland is not necessarily an area where more implies better.

In terms of efficiency, figure 3.58 shows that because health expenditure (in constant prices) increased at a faster rate than activity over this period, the efficiency index for both Northern Ireland and the UK as a whole followed a similar downward trend between 1999/00 and 2003/04. However, it should be highlighted that these charts are meant to be indicative of general trends and DHSSPS have significant reservations regarding their use.

Figure 3.58: The Costs Weighted Efficiency Index (CWEI) of Healthcare Services fell by almost 15% in the UK and Northern Ireland between 1997/98 and 2003/04.



Source: DHSSPS, National Statistics

In response to problems with traditional measures of efficiency and productivity a review was commissioned by the ONS on the measurement of Government output. Although the review published its final report in January 2005 it is expected to be some time before useful results become available [73].

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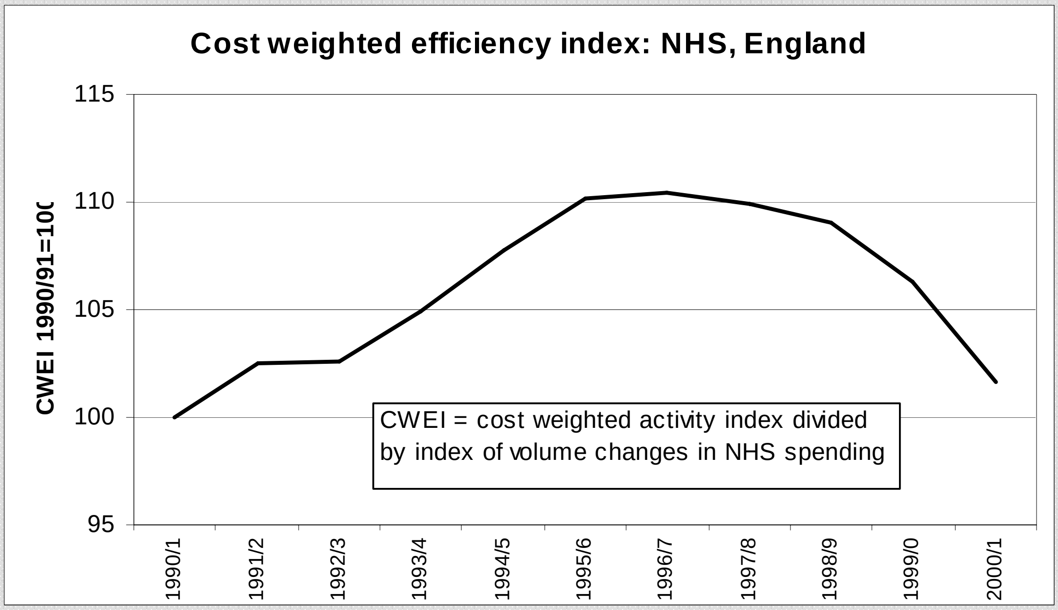
[72] Collectively they account for 78% of the growth in weighted activity excluding dental services for which data is not available over the entire period.

[73] Atkinson Review Final report: Measurement of Government Output and Productivity for the National Accounts, 2005

Box 3.6: Problems with traditional measures of health care productivity and efficiency



The reason for the falling trend in the above graph is straightforward: As the traditional productivity measure is a ratio of outputs (activity) to inputs (money), and as there have been relatively large increases in NHS spending since 1997/8 without similar increase in outputs, the ratio of outputs to inputs must fall. With spending rising even faster since 2000/01, this downward trend is likely to have continued in subsequent years.

Although the reason for the trend is straightforward, its interpretation is less so. There are essentially four reasons underlying the downward trend in efficiency:

Extra spending has in part been:

- **absorbed by higher costs (rather than higher outputs).**

  In other words, productivity has actually fallen in some areas

- **invested in services and activities which may take some years to be reflected in increased outputs.**

  Spending on preventative services such as smoking cessation classes or dietary advice, may not yield their full measurable results sometime after the year in which the spending on these services took place.

- **increasingly channelled into activities not captured by the productivity measure.**

  The cost weighted efficiency measure, for example, does not record clinics held in GP surgeries, which may often act as a substitute for activities usually carried out in hospitals.

- **used to increase the (unmeasured) *quality* rather than the (measured) *volume* of outputs.**

  Devoting more time to each patient improves the quality of care (and costs), but is not captured by current productivity measures.

It may seem somewhat paradoxical, but it is not always in the patient's interests for the NHS to always do more activity - even if this improves measured productivity. It is not, for example, necessarily desirable for the NHS to continually increase the number of admissions to its casualty departments; prevention is better. And as some drugs (and some operations and other interventions) are only of very limited benefit to patients it makes little sense for the NHS to strive to provide more.

For the NHS, improving productivity is not just about producing more of everything for each extra pound, it is about doing the right things in the right way as efficiently as possible.

Due to the weaknesses of the overall macro indicators, significant weight is often given to micro indicators of performance such as waiting lists and times, cancellation rates, GP referral rates, day case rates etc. However, each of these indicators needs to be considered in context. For example, high waiting lists may reflect high levels of demand rather than inefficient delivery, whilst a very high rate of bed occupancy may exacerbate the risk of hospital acquired Infections.
Here, using currently available data, we examine the efficiency of various sectors of the health and social care system in Northern Ireland, wherever possible and appropriate, making comparisons with other regions of the UK. As already noted, largely for historical reasons, there is a bias towards the acute health care sector in terms of the measures available to provide indicators of efficiency and productivity. In considering the effectiveness of acute service provision in Northern Ireland, the 2002 Needs and Effectiveness Evaluation (NEE) presented evidence that unit costs were higher and productivity was lower in Northern Ireland than England, with part of the explanation for this being attributable to higher lengths of stay. However, little were made of these findings and it was also stated that Northern Ireland performed better in terms of other indicators of performance (such as readmission rates) but with little in the form of supporting data.

A key statement from the NEE was that, *"Productivity in the hospital sector has increased by almost 100% over the last 10 years"***.** This was based on growth in throughput (that is, day case and inpatient activity per available bed) - which increased by 97% in Northern Ireland between 1991/92 and 2000/01 compared to 71% in England. It is worth noting however, that despite this greater increase in throughput, by 2000/01 productivity in Northern Ireland was still 19% lower than in England. In addition, subsequent growth in throughput has averaged only 2.5% per year in Northern Ireland compared to 3.0% in England.

These calculations include renal dialysis treatments not included in GB data as referred to in Section 3.3.1. Excluding these treatments the growth in Northern Ireland throughput between 1991/92 and 2000/01 falls to 83% whilst 2003/04 throughput is 26% below the level in England.

3.7.1 Hospital activity and labour inputs

Throughput is one measure of the utilisation of a key resource - beds. However, there are other ways of looking at the efficiency with which a system uses the resources at its disposal.

For example, although Northern Ireland has higher levels of hospital activity than the UK average (see section 3.2.2), it also has significantly higher levels of staffing, and figure 3.59 shows that Northern Ireland, Wales and Scotland have significantly *lower* level of labour productivity than English regions, with hospital activity per staff member in the Northern Ireland health care sector approximately 19% lower than the UK average (and 16% below on unadjusted basis)[74].

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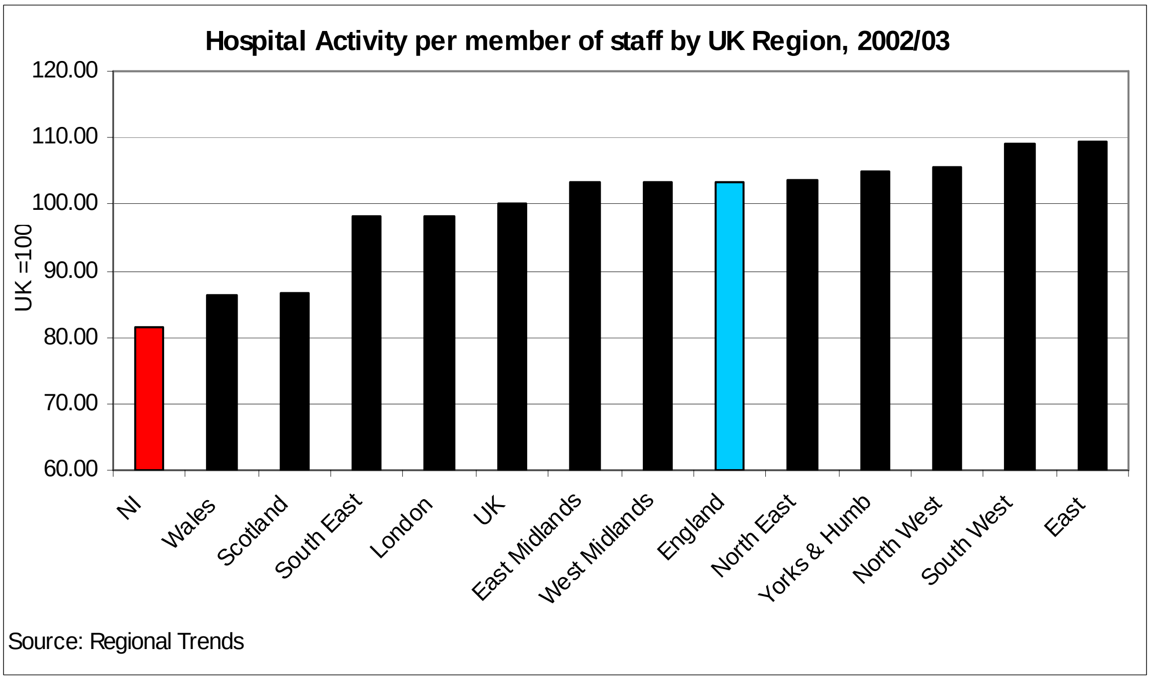
[74] Unweighted activity is simply the summation of the number of inpatients, outpatients, day cases and A&E attendances. Weighted activity is the sum of each activity weighted by the respective unit cost for England. Inpatients have a weighting of 20.9 compared to 7.1 for day cases and 1 each for outpatients and A&E.

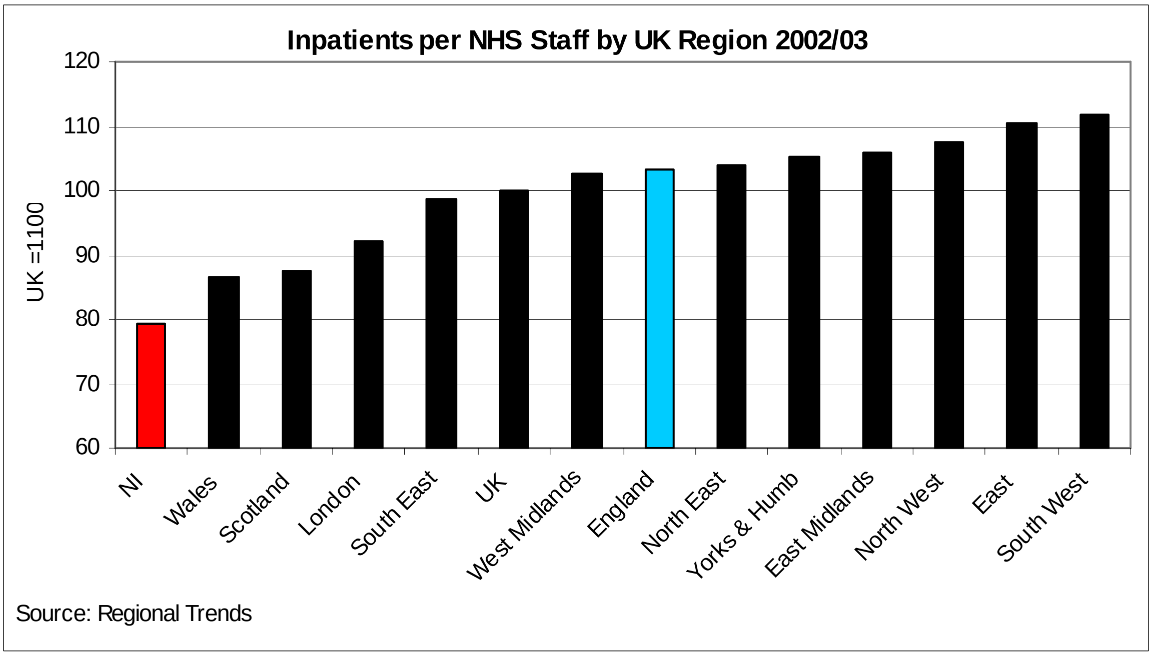
Figure 3.59: Hospital activity (weighted) per member of staff in Northern Ireland is the lowest of the UK regions, 2002/03



Source: Regional Trends

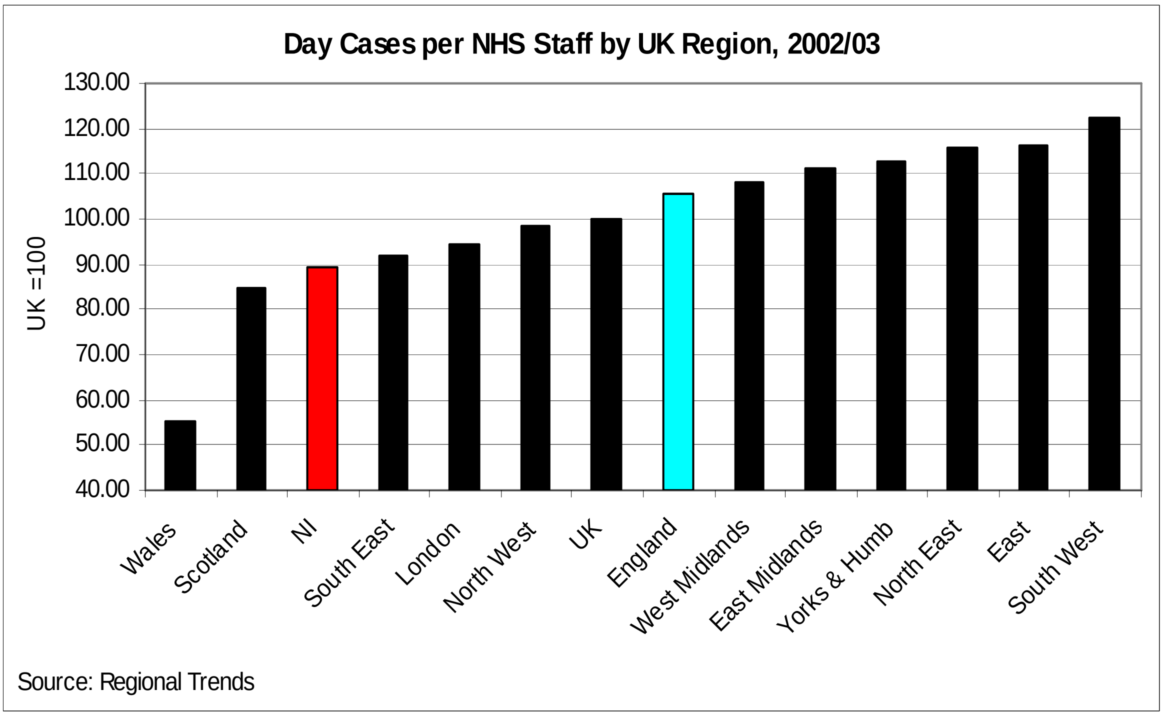
Although it was not possible to split staff between activities, figures 3.60-3.63 below compare levels of inpatients, outpatients, day cases and A&E attendances with the total number of HCHS staff for each UK region as a broad indicator of labour productivity. It can be seen for inpatients, outpatients and day cases that HCHS labour productivity in Northern Ireland is significantly below the UK average. Whilst labour productivity in Northern Ireland is higher in terms of A&E attendances, the significant variation with other forms of activity raises questions as to whether the level of activity reflects actual need or that it might be better for treatment to be provided in an alternative form.

Figure 3.60: The number of inpatients treated per HCHS staff member in Northern Ireland is 21% lower than the UK average.



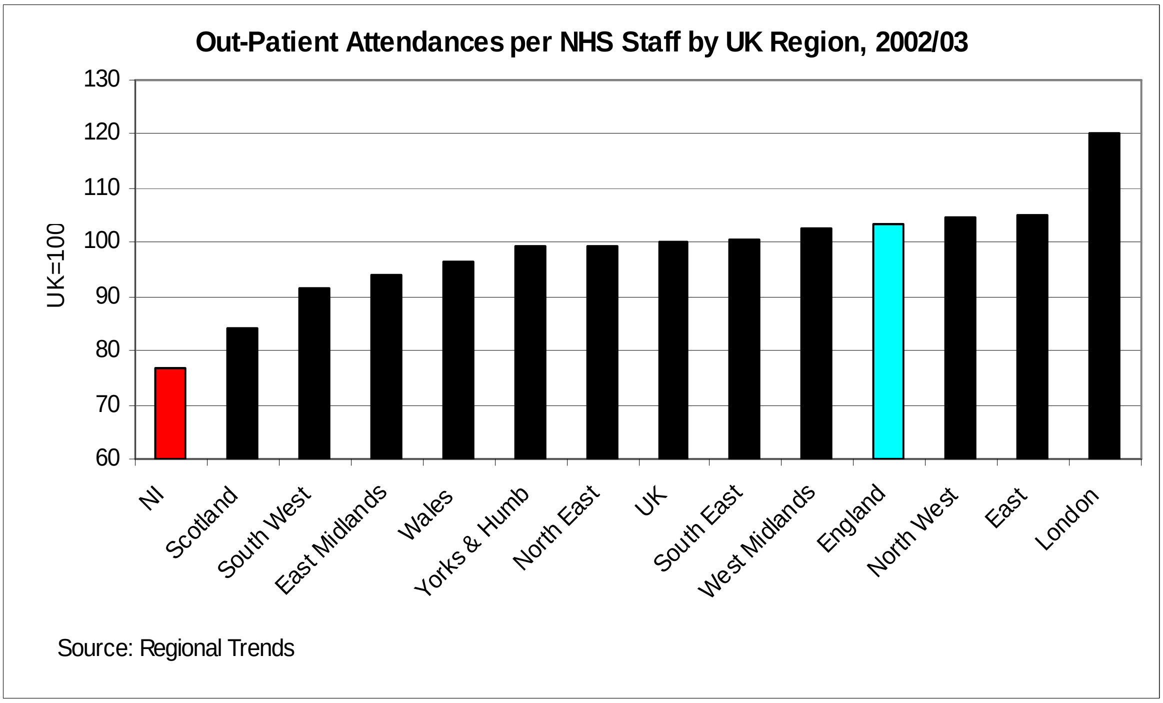
Source: Regional Trends

Figure 3.61: The number of day cases per HCHS staff member is 11% lower than the UK average.



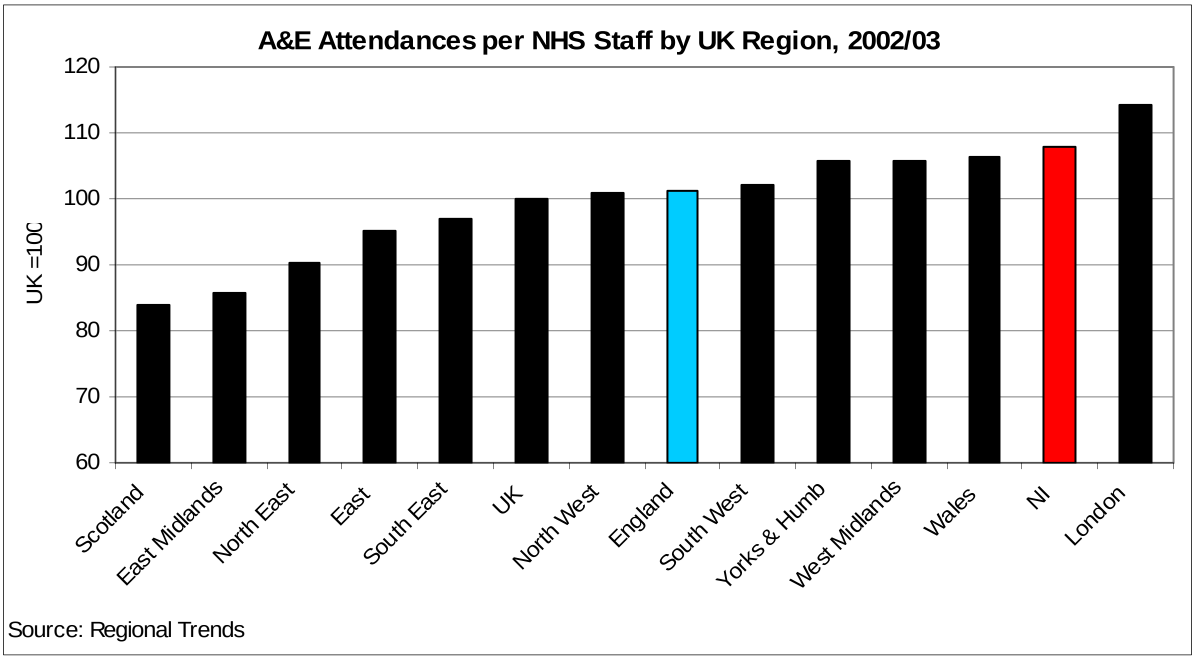
Source: Regional Trends

Figure 3.62: The number of outpatients treated per HCHS staff member is the lowest of all UK regions



Source: Regional Trends

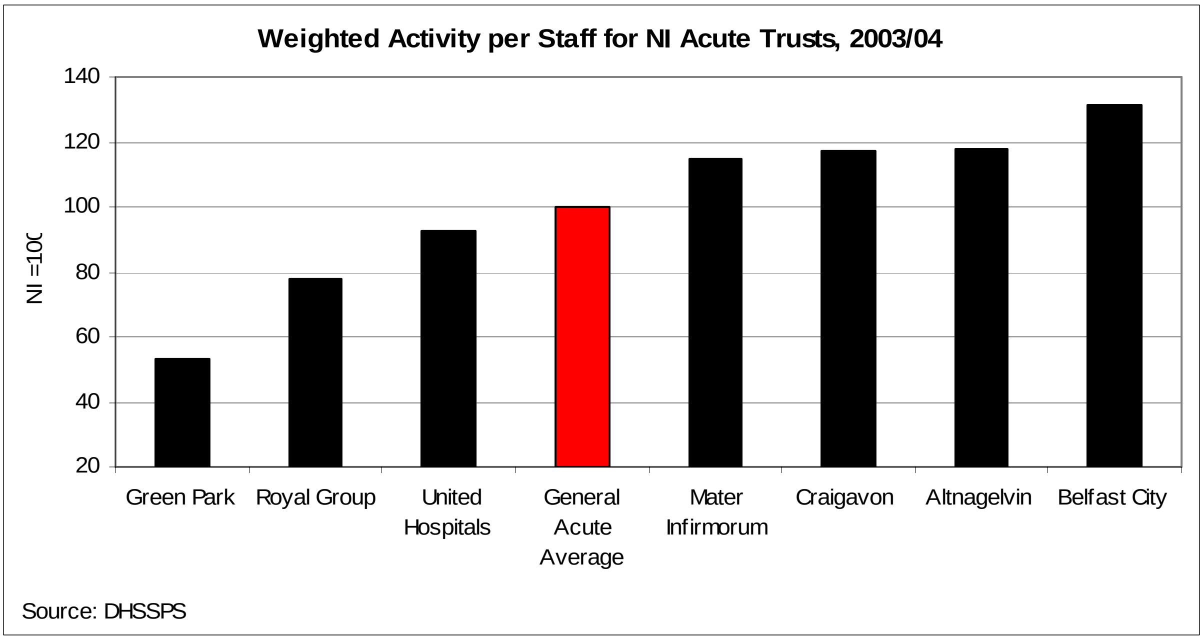
Figure 3.63: The number of A&E attendances per HCHS staff member is 8% higher than the UK average



Source: Regional Trends

There are also significant variations in the level of activity per staff member between Northern Ireland hospitals. Figure 3.64 compares the weighted level of activity for General Acute Hospitals in Northern Ireland. It can be seen that weighted activity per staff is 31% higher in the Belfast City Trust than the average for Northern Ireland whilst in the Green Park Trust labour productivity is 47% below the average. However, these comparisons need to be treated with care given differences in case mix with the Royal and Greenpark Trusts carrying out the main regional medical specialties.

Figure 3.64: There are significant variations in the level of weighted hospital activity per staff for Northern Ireland general acute trusts, 2003/04



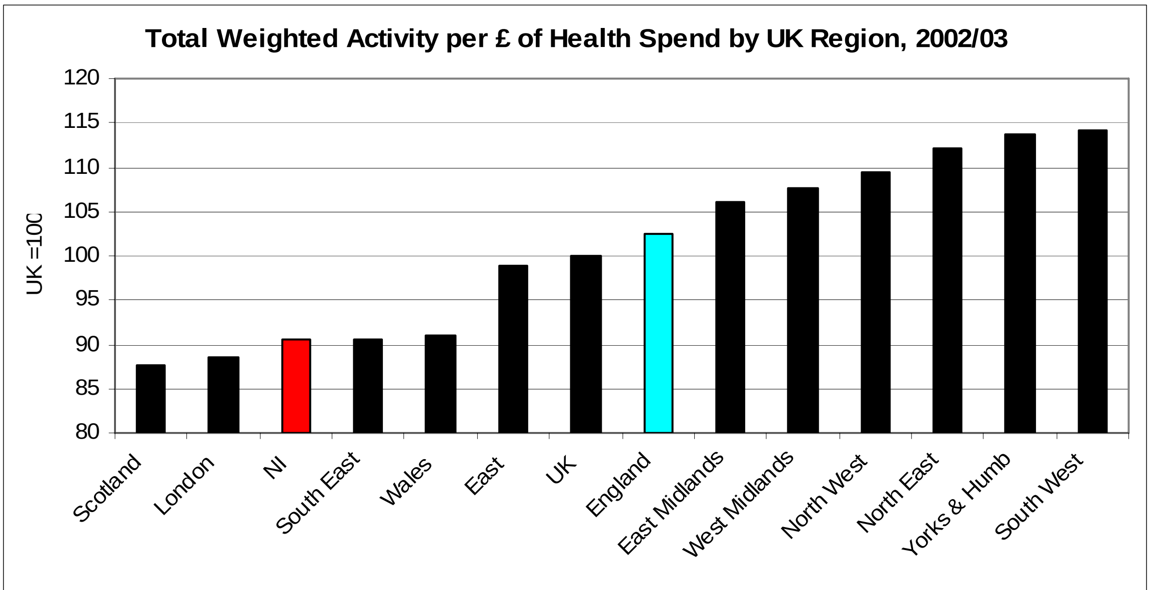
Source: DHSSPS

3.7.2 Hospital activity and total financial inputs

Whilst labour is a significant input into the provision of health care services, it is not the only one. In addition, variations in labour input mix across the different regions of the UK (which have not been taken into account above) can affect regions' relative positions.

A more general measure of inputs is the total financial resources devoted to health care. Figure 3.65, for example, shows that hospital activity per health care pound in Northern Ireland is 9% lower than the UK average (7% unadjusted for the different unit cost of activities). If Northern Ireland were to achieve the same level of efficiency as England, this would allow, for example, an additional 45,000 inpatients to be treated each year - equivalent to the entire inpatient waiting list[75].

Figure 3.65: Hospital Activity (weighted) per £ identifiable Health spend is 9% lower in Northern Ireland than the UK average, 2002/03



Source: Regional Trends, PESA

3.7.3 Unit costs of hospital activity

At a more micro level, it is also possible to examine the unit costs (also termed reference costs) of individual defined groupings of like hospital procedures that are considered to consume like resources- health care resource groups (HRGs).

Such data allows for comparison both at the level of trusts across Northern Ireland and with England. Figure 3.66 shows that the average cost per procedure (aggregated up from individual procedures into elective inpatients, non-elective cases and day cases) in the acute sector in Northern Ireland for 2002/03[76] was 6%

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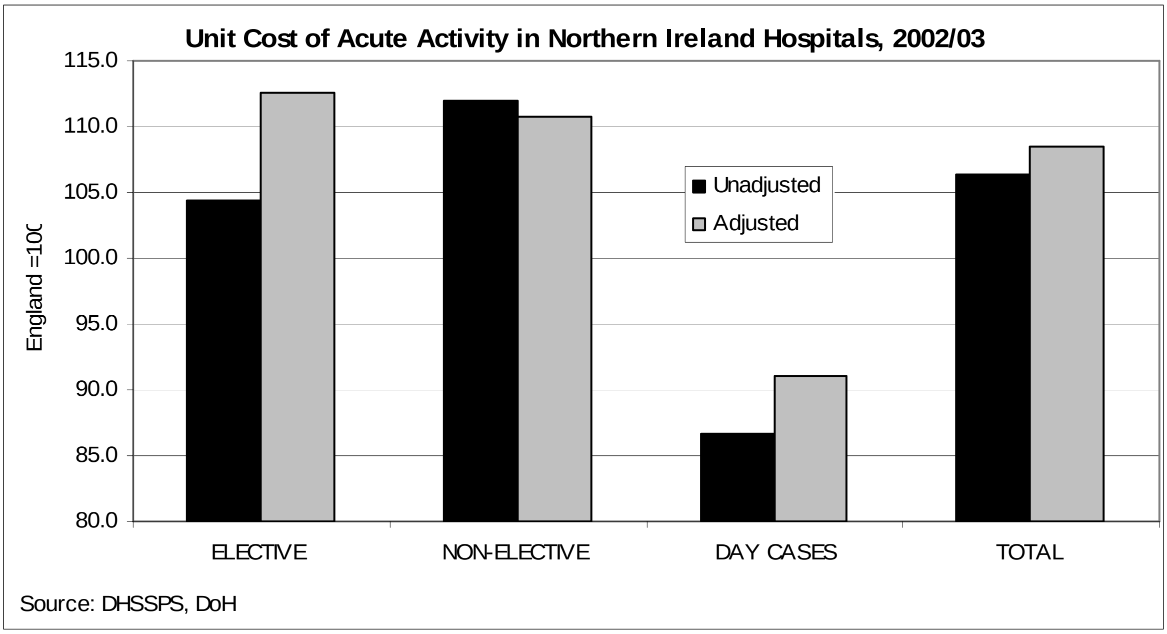
[75] Based on 9.4% of weighted activity divided by the weighting for inpatient activity (20.9)

[76] The unit cost data covers approximately £450m of the £708m acute budget in 2002/03. It is estimated that approximately £66m of the £450m could be saved if Northern Ireland matched the performance of England in terms of the HRGS where unit costs are currently lower in England. Whilst DHSSPS consider that only £25m could be saved this is on the basis that Northern Ireland matches England even in those areas where costs are currently higher ie unit costs would be allowed to fall which is clearly illogical.

higher than in England. However, given that the case mix in England tends to be distributed towards more expensive procedures, adjusting for case-mix results in unit costs being 9% higher in Northern Ireland compared with England[77].

There are significant variations within this overall figure. Day case unit costs are 9% lower than in England, while elective inpatient costs are 13% higher, with non-elective costs being similar. As the length of stay for elective procedures in Northern Ireland is 7% lower than in England (although later it will be shown that for all in-patient activity the length of stay is higher in Northern Ireland), this would indicate that per diem unit costs in Northern Ireland are even higher than this. In addition, in England unit costs are also adjusted when making comparisons between Trusts by a market forces factor to reflect differences in the underlying cost base of different areas. The lower level of costs in Northern Ireland would imply that unit costs are even further from the English than the figures above would suggest[78].DHSSPS have indicated that a significant element of the difference in unit costs is due to maternity provision which, the Department state, is of a higher standard in Northern Ireland than England.

Figure 3.66: 2002/03 Unit Costs in Northern Ireland Acute Sector (England =100)



Source: DHSSPS, DoH

At a more disaggregated level, figure 3.67 shows average unit costs for Northern Ireland relative to the English average (=100) across groups of procedures. For nearly all groups, Northern Ireland has higher unit costs for elective procedures than England (with the exception of cardiac surgery, where unit costs are 9% lower). In contrast, spinal surgery costs are 42% higher in Northern Ireland than England.

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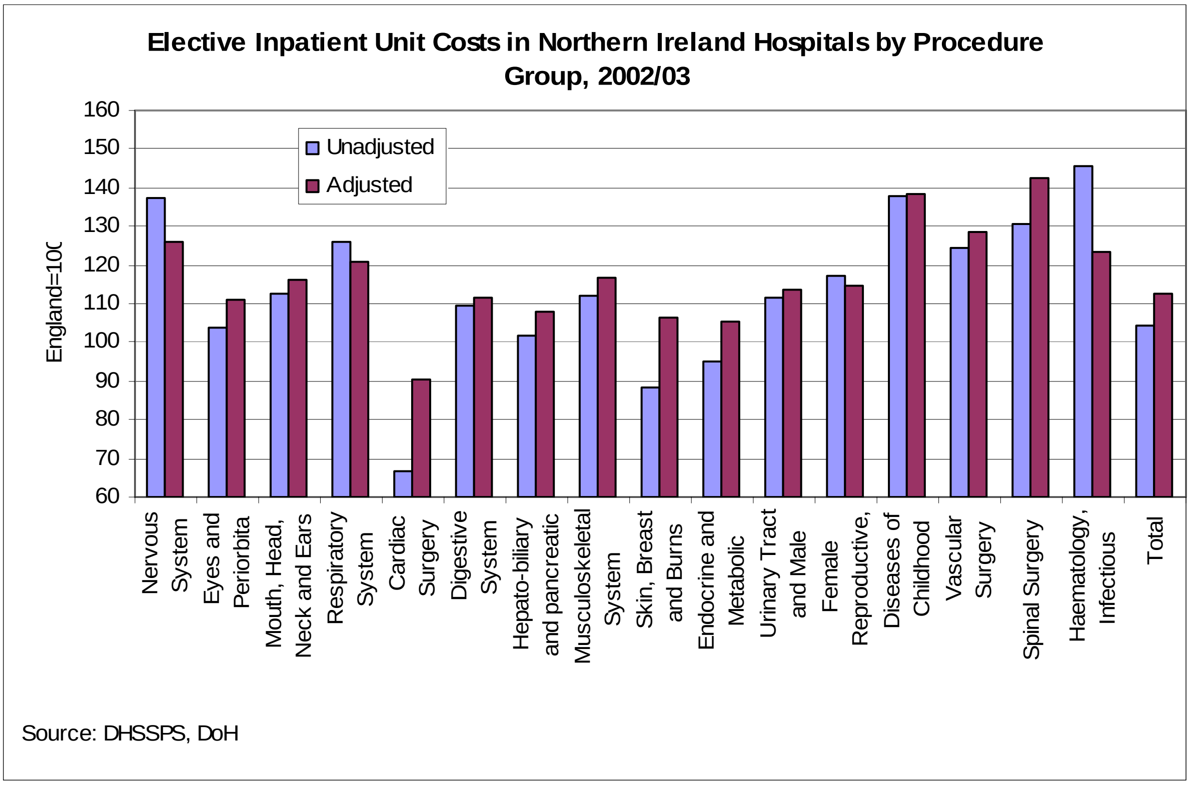
[77] Adjusting for case mix involved weighting English unit cost data per procedure by the Northern Ireland distribution of FCE's between procedures.

[78] DHSSPS have indicated that some of the difference in unit costs is due to methodology rather than efficiency for example in respect of funding for older Specialist Registrar posts for junior doctors and the non exclusion of discrete coronary care units from NI HRGs.

F***igure 3.67: Elective Inpatient unit costs are higher in Northern Ireland than England for most procedure groups, 2002/03***



Source: DHSSPS, DoH

Within Northern Ireland there are also significant variations between trusts - but this appears to be mostly related to trust size. Figure 3.68 shows that there are a number of hospitals in Northern Ireland where the average unit cost of procedures is comparable to the average for England.

However, there are also trusts which have costs substantially higher than the Northern Ireland average. These tend to carry out only small amounts of acute activity. This corresponds to the view of some of the people we met who suggested that the continued provision of services in hospital below a certain scale was inefficient. However, given their relatively small scale, removing the three smallest Trusts[79] from the analysis only marginally reduces Northern Ireland's overall unit cost. In contrast, if the Royal Group of Hospitals and Greenpark Hospital Trust were excluded, this would be sufficient to remove the cost difference with England. DHSSPS have argued that these findings reflect those found elsewhere: that small and large hospitals tend to have higher unit costs. However, this begs the question of the appropriate size - both in efficiency and clinical terms - for Northern Ireland hospitals and the opportunity costs currently born as a result of maintaining the current configuration of hospitals.

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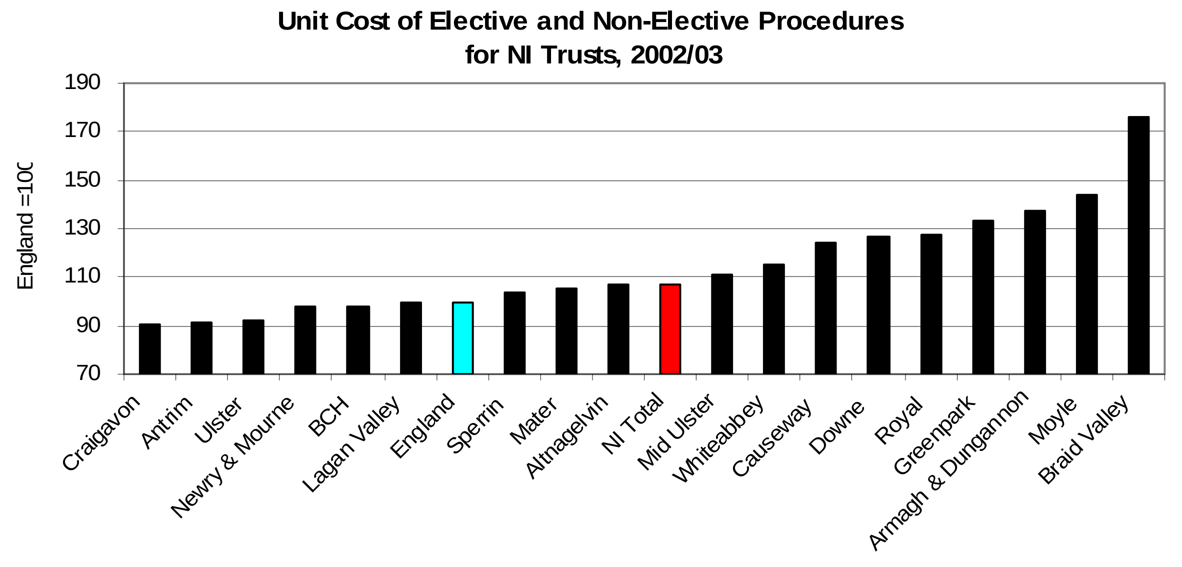
[79] Armagh & Dungannon , Braid and Moyle

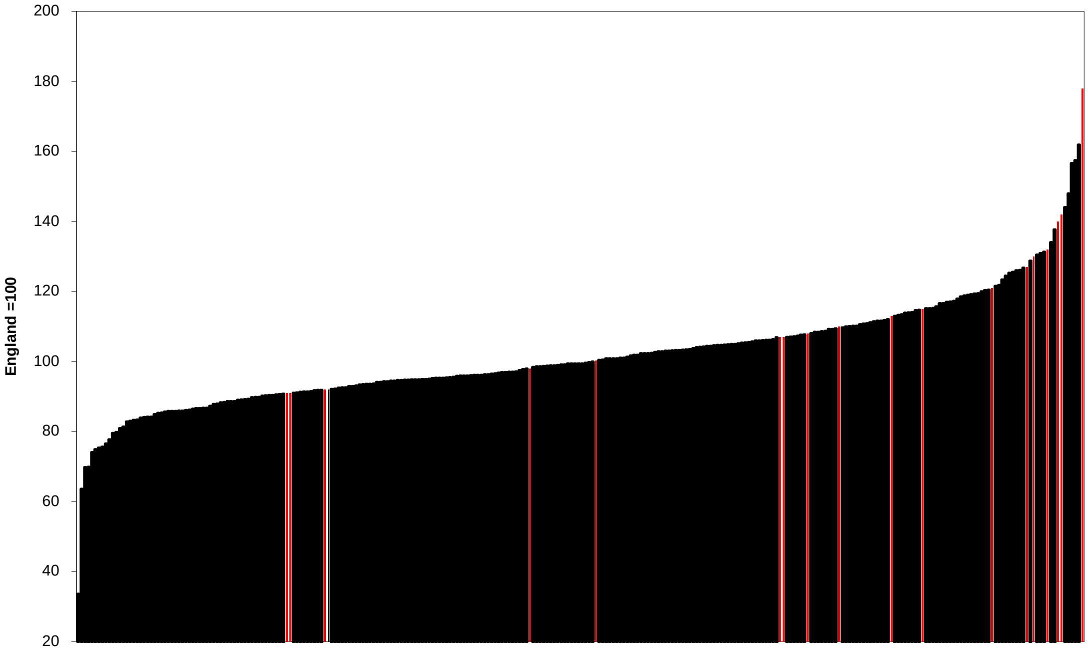
Figure 3.68: The Unit Cost of Elective and Non-Elective Procedures for most Northern Ireland Acute Hospital Trusts is above the average for England, 2002/03



Source: DHSSPS, DoH

It is important to recognise that there is also significant variation in the unit cost of procedures for NHS trusts in England. Figure 3.69 highlights the performance of Northern Ireland acute trusts against the range of trusts in England. It can be seen that whilst a minority of Northern Ireland hospitals are below the English average, a majority are above - some in the top 10%.

Figure 3.69: Unit cost of procedures for Northern Ireland trusts compared to NHS Trusts in England, 2002/03



Source: DHSSPS, DoH

This section has shown that there are in general lower level of productivity and efficiency in hospitals in Northern Ireland than England although performance appears to be better than in Scotland and Wales. Section 3.83 will show that in recent years the level of activity has not risen to the same extent as staff in the

HCHS sector throughout the UK countries. There is therefore clear scope for efficiency gains if the performance in England could be matched particularly if reforms in England, such as payment by results, return productivity to the levels seen in the late 1990's. Whilst policy makers in Northern Ireland may decide that the required adjustments to the system here are not appropriate, for example reduced level of service for rural communities, the opportunity cost of such decisions need to be recognised.

> **Recommendation 13: Investigate ways to reduce unit cost variations through incentive mechanisms such as tariff-based activity payment/budget setting systems**
>
> **Recommendation 14: Further investigation is needed to explore possible reasons for high unit costs at the Royal and Green Park Trusts.**

3.7.3 Theatre Usage

A key resource within hospitals is operating theatres. A recent report from the Northern Ireland Audit Office[80] indicated that there was significant unused capacity in the system given that theatres were only intended for use (that is, available) 63% of the available time. DHSSPS have argued that because of the need to have theatres dedicated to particular specialties a better indicator is the proportion of *planned* hours that were used, and that on this measure the 2002 Healthcare Commission Acute Hospital Portfolio illustrated that the mean across Northern Ireland was 74% compared to 73% across English and Welsh trusts.

In addition , whilst the overall cancellation rate of 6.4% was within the bench mark target of 10%, there were significant variations between individual specialties. In particular, the cancellation rate for cardiac surgery was 36% whilst that for plastic surgery was 9% (2001/02 data)[81].

Over the past two years there has been general progress in this area, with a 6% increase in intended theatre sessions and a fall in the cancellation rate to 5% (although this still means that theatres are only used for 68% of the time). There has been progress too in reducing the cardiac surgery cancellation rate - now down to 24%. However, this appears to have been achieved largely by cutting the number of intended sessions by more than half[82]. In addition, cancellation rates for plastic surgery have increased to 32% whilst those for thoracic surgery have increased from 3% to 16% over the period.

3.7.4 Day case work

Where appropriate in terms of medical technology and patients' health status, many operations once requiring overnight stays in hospital as an inpatient are now carried out as day cases. This is not only a more efficient use of scarce hospital resources,

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[80] *The Use of Operating Theatres in the Northern Ireland Health and Personal Social Services*, NIAO, 2003

[81] A higher cancellation rate is to be expected for cardiac surgery due to the dependence on patients' fitness for surgery.

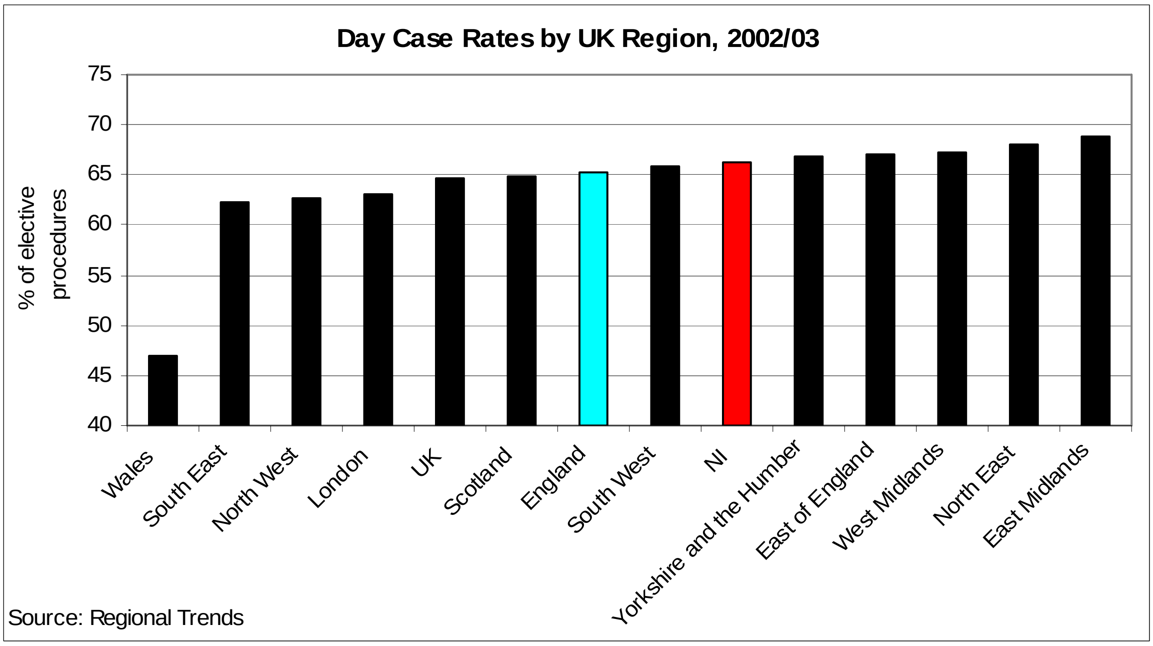
[82] DHSSPS have indicated that this was due to changes in cardiac procedure casemix, with less invasive procedures now available and only the more complicated cases resulting in operations.

but better for patients. As a result, rates of day case work have generally been increasing in all health care systems.

A 2001/02 DHSPSS commissioned report into value for money aspects of day case work in Northern Ireland[83] found that compared with England, a higher proportion of day case activity in Northern Ireland was *inappropriate* in terms of, for example, minor procedures that should be carried out in treatment rooms or outpatient departments. At the same time, too many patients were being treated as in-patients when treatment as a day case would have been more appropriate. Out of eighteen procedures investigated, there were only five for which Northern Ireland hospitals had the same or higher rates than in England and Wales. In addition, whilst the level of throughput per staff member was higher in Northern Ireland, at 6.5%, the rate of non-attendance was significantly higher.

In terms of more recent performance, figure 3.70 shows that day cases account for 66% of elective day and inpatient activity in Northern Ireland compared to 65% for the UK as a whole - although there does not appear to be significant variation across UK regions, with the exception of Wales.

Figure 3.70: Northern Ireland has the sixth highest day case rate of UK Regions, 2002/03



Source: Regional Trends

Figure 3.71 shows that there has been a significant increase in the day case rate across the UK in the past decade.

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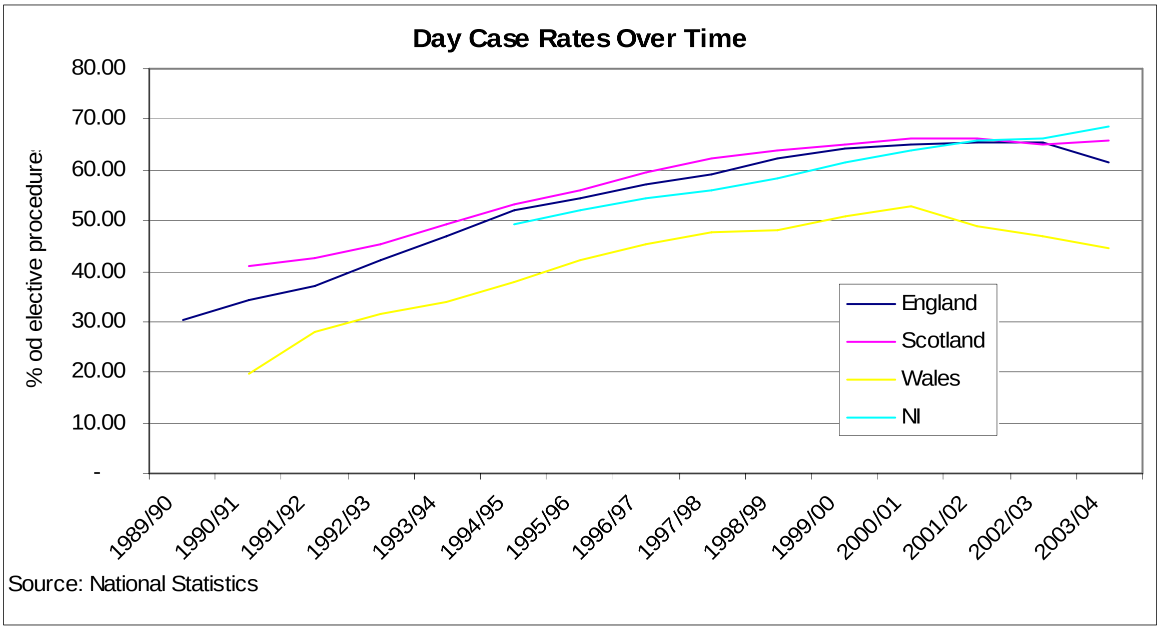
[83] *Day Surgery in Northern Ireland*, Regional Summary of Acute Hospital Portfolio, DHSSPS (October 2003)

Figure 3.71: Northern Ireland, England and Scotland have experienced broadly similar upward trends in day case rates.



Source: National Statistics

However, day case rates in Scotland and England appear to have reached a plateau in recent years, although the fall in the English day case rate in 2003/04 was due to a substantial increase in elective inpatient activity[84]. In Northern Ireland, which previously had lower day case rates than in England and Scotland, the upward trend has continued although this has been due to a fall in elective inpatient activity. Wales is the clear outlier in terms of day case rates although it is not clear whether this reflects differences in activity or data collection.

3.7.5 Length of Stay

Reductions in length of stay have been a long term trend across all health care systems and have been one of the main sources of improvement in efficiency and productivity. Length of stay is clearly important in terms of efficiency as the longer a person stays in hospital, the greater the cost.

The 2002 NEE recognised that the average length of stay in Northern Ireland hospitals was slightly longer than in comparative regions although this was in part explained by differences in measurement and policy. Figure 3.72 shows that although the average length of stay is higher in Northern Ireland than in England, it is lower than in Scotland and Wales.

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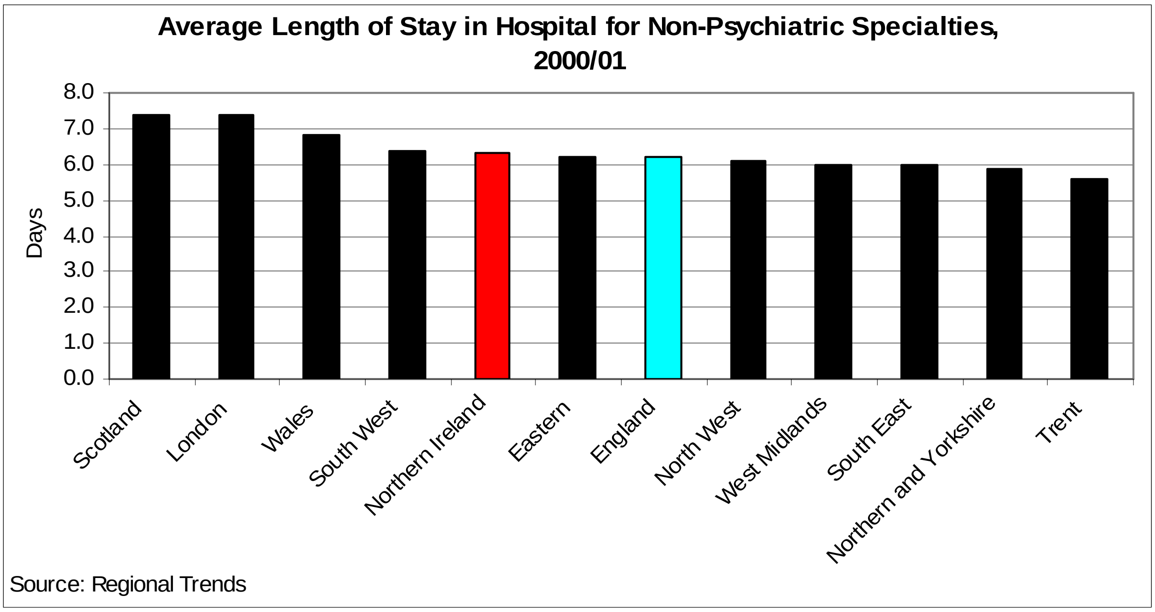
[84] The increase in elective inpatient activity of 37.1%recorded for 2003/04 is higher than that which would be reasonably expected. It has however not been possible to obtain a definitive explanation for the increase.

Figure 3.72: Average Length of Stay in Hospital for Non-Psychiatric Specialties (Mean Days), 2000-01



Source: Regional Trends

More recently, figure 3.73 compares the average length of stay in Northern Ireland with England for a range of specialties. Whilst the average length of stay of stay in Northern Ireland is 6% greater than in England it can be seen that there are significant variations between specialties. For example, for general medicine and general surgery, which together account for over a third of the deaths and discharges, Northern Ireland has a lower length of stay than England. In addition, geriatric medicine, in which the average length of stay is 32.3 days in Northern Ireland compared to 21.9 days in England, accounts for almost all the variation between the countries[85].

Overall, the average length of stay for treatment in Northern Ireland hospitals has fallen from 9.4 days in 1995/96 to 7.8 days in 2003/04. However, most of the decline occurred between 1995/96 and 1998/99, since when the average length of stay has remained broadly stable Whilst the average length of stay has fallen for all Programmes of Care over the past decade, figure 3.74 shows that the largest falls have been in Mental Health and Learning Disability.

A key factor determining length of stay is bed management. This issue was considered as part of the 2002 Acute Hospital Portfolio analysis[86]. It was found that a higher proportion of beds in Northern Ireland than England were occupied by patients who should have been in a different type of bed representing an inefficient use of resources as well as reducing quality of care.

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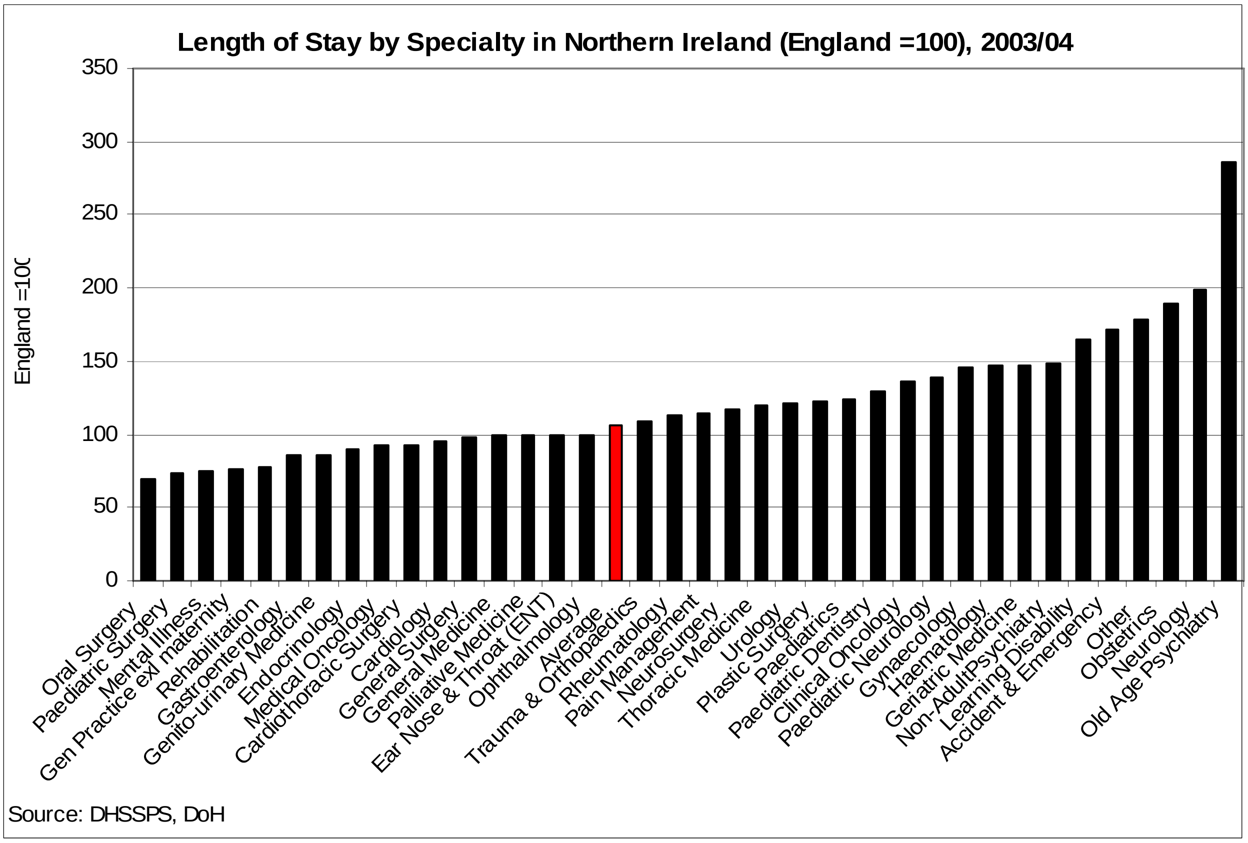
[85] If the Geriatric Medicine Inpatient specialty in NI Trusts had the same level of length of stay as in England, this would reduce the average length of stay to 7.7, slightly above the 7.6 figure for England.
[86] Acute Hospital Portfolio Year 3 Draft Regional Report, DHSSPS

Figure 3.73: Mean Length of Stay by Specialty in Northern Ireland (England=100), 2003/04



Source: DHSSPS, DoH

Overall, there is scope for reductions in the average length of stay in Northern Ireland. If the average length of stay in England from figure 3.73 was matched in Northern Ireland this would potentially free up bed capacity to treat an additional 18,000 inpatients or perhaps more appropriately 700 more Geriatric medicine patients given that this appears to be the main cause of the differential[87]. It should be noted that the 2005/06 Priorities for Action contains a target that the average length of stay for patients should be reduced by 5% in 2005/06 and a further 5% in 2006/07 compared to 2004/05 levels.

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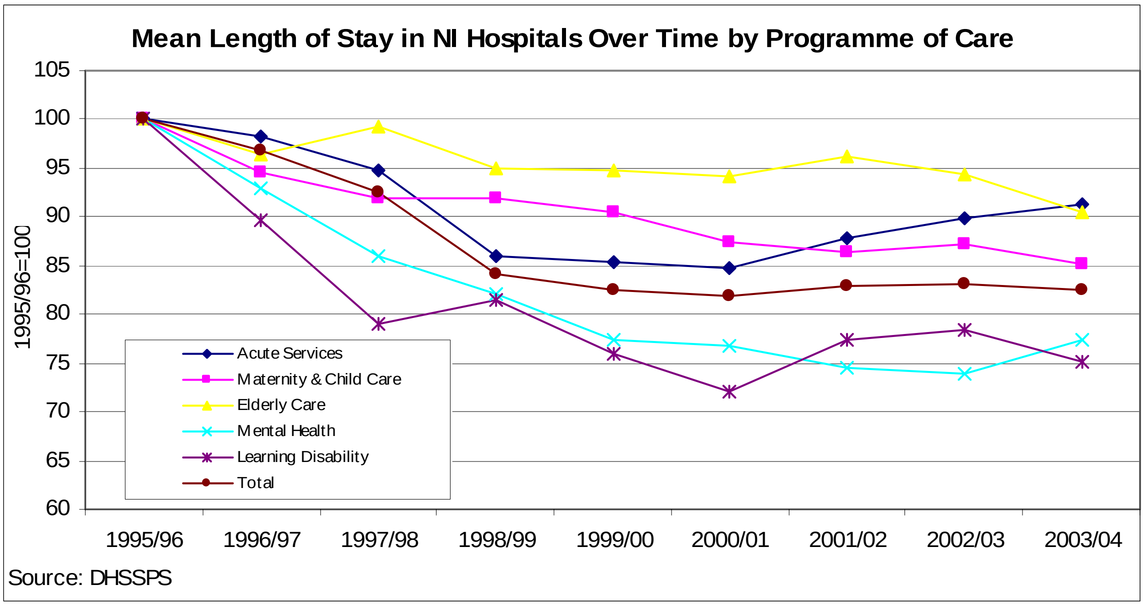
[87] Calculated as current number of NI deaths and discharges minus NI occupied beds divided by length of stay in England.

Figure 3.74: Length of Stay in Northern Ireland Trusts has fallen across all by Programmes of Care.



Source: DHSSPS

Recommendation 15: Investigate scope for further reductions in length of stay and avoidance of admission to hospital

Recommendation 16: Aim in medium term to use outcome-based productivity measures.

3.8 Workforce and pay

A key element of health and social service delivery is the recruitment, retention and motivation of sufficient numbers of appropriately skilled staff. Health and social services are labour intensive sectors, with direct staff costs accounting for around two-thirds of total spending. Therefore, whilst the workforce is critical to delivery, it is also important to make every effort that the significant costs associated with this input are minimised as far as possible, while balancing the demands of the system, patients, taxpayers and staff.

The importance of workforce issues is reflected in the focus of a number of major reports and reviews recently. The Wanless Review[88], for example, indicated that a significant increase in health care staff will be required over the next 20 years to deliver a new 'vision' of care envisaged by the review. In addition, workforce issues were considered as part of the 2002 Needs and Effectiveness Evaluation[89]. More recently, the DHSSPS has published results from a series of uni-professional workforce reviews, whilst the Department of Finance and Personnel has produced a Pay and Workforce Strategy for the Northern Ireland Executive Departments with a major focus on health[90].

Here we consider the current availability and future requirements of staffing resource for health and social services in Northern Ireland and whether these resources could be used more effectively and efficiently. It is important to note at the outset that unlike other aspects of health and social care services where distinct Northern Irish policies are developed, in terms of the pay and conditions of staff, Northern Ireland tends to mirror the position in Great Britain.

3.8.1 Historic staffing trends and comparisons

Currently, there are around 110,000 people employed in health and social care in Northern Ireland, equivalent to nearly 6.4% of the entire population and around 28% more than in the UK as a whole[91]. In turn there are approximately 68,000 people employed directly as public servants in NHS Trusts in Northern Ireland[92]. In addition, of course, there are thousands of people providing care and support in the form of charities, friends and relations, without whom the formal health care system would be under unsustainable pressure.

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[88] Securing our Future Health: Taking a Lon-Term View, Final Report of the Wanless Review, April 2002

[89] Effectiveness Evaluation: Health and Social Care, DHSSPS

[90] Northern Ireland Pay and Workforce Strategy 2004, DFP

[91] There are 3 million employee jobs in SIC N (Health & Social Work) in the UK as a whole equivalent to 5.0% of the population.

[92] The main difference between the two figures are those employed in the provision of social services but not by the public sector, including those working in independent nursing and residential homes- however, to the extent that the public sector funds such services, these workers can be considered to be indirectly employed by the public sector. The latter figure also does not include GP,s, Pharmacists, Dentists and Opticians working in Family Practitioner Services. .

Figure 3.75: Trends in health service employment in Northern Ireland are similar to those in other countries

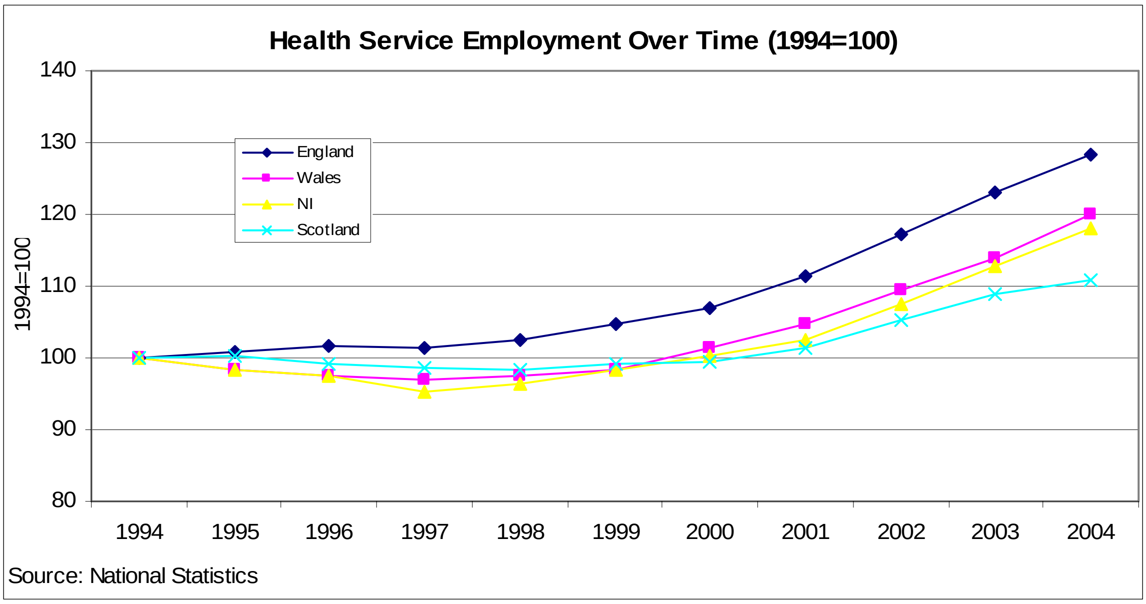

Figure 3.75 shows that in common with Wales and Scotland, Northern Ireland experienced a decline in NHS employment in the mid 1990's - possibly linked to the contracting out of services. More recently, all UK countries have experienced growth in numbers of health care staff, with England experiencing the fastest growth - although the base for England was, and remains lower.

Whilst differences in the coverage of workforce statistics for the UK countries makes overall comparisons of staffing levels difficult, Figure 3.76 compares the number of hospital and community health service (HCHS) staff, qualified nurses and medical & dental staff per head of population.

It can be seen that Northern Ireland has significantly higher levels of total HCHS staff per head of population than the rest of the UK. However, as the Interim Wanless Report highlighted, the UK as a whole has substantially fewer doctors and nurses than many other western industrialised countries[93]. Although it may be the case that England has too few health care staff rather than Northern Ireland having too many, the public sector funding parameters currently applying in the UK mean that it is the position in England that is most relevant when considering Northern Ireland's relative level of provision.

A particular issue in the Needs and Effectiveness Evaluation was the level of administrative & clerical staff in the Health & Personal Social Services (HPSS) sector. It was shown that this staff group accounted for broadly the same share of overall HPSS staff in Northern Ireland as England in 1999. However, between 1999 and 2003 the number of administrative & clerical staff increased by 20% in Northern compared to just under 3% in England - which meant that there were 43% *more* administrative & clerical staff per head of population employed in the HPSS sector in Northern Ireland than in England(although at least part of this difference may be due

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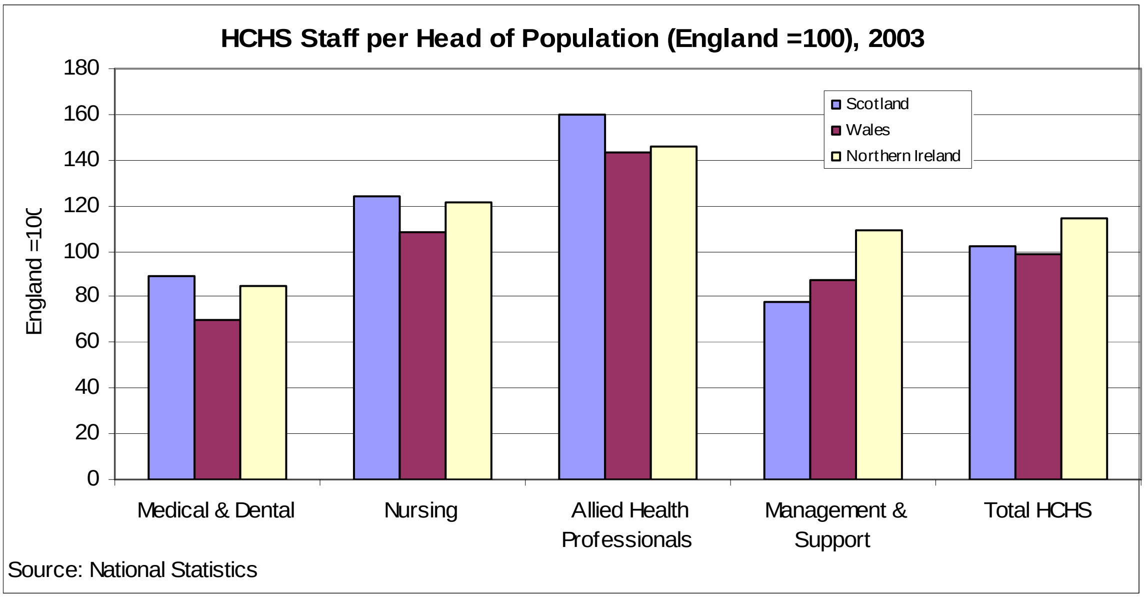
[93] Paragraph 11.17, Wanless Interim Report, HM Treasury

to definitional differences in the way staff are catagorised between the two countries)[94].

Figure 3.76: Northern Ireland has over 10% more HCHS staff per head of population than England



Source: National Statistics

In terms of the major staff groups employed outside of the HCHS, there are 6% more GPs per head of population in Northern Ireland than England and 4% more personal social services staff. However, Northern Ireland's staffing compliment for both these groups per head of population is lower than in Wales and Scotland.

Figure 3.77 shows that the largest grouping in the health and social care workforce is qualified nursing & midwifery staff (28%), followed by administration & clerical staff (23%). However, since 1994, the fastest growth in staff numbers has occurred in the professional & technical staff grouping - which includes physiotherapists, radiographers and dieticians.

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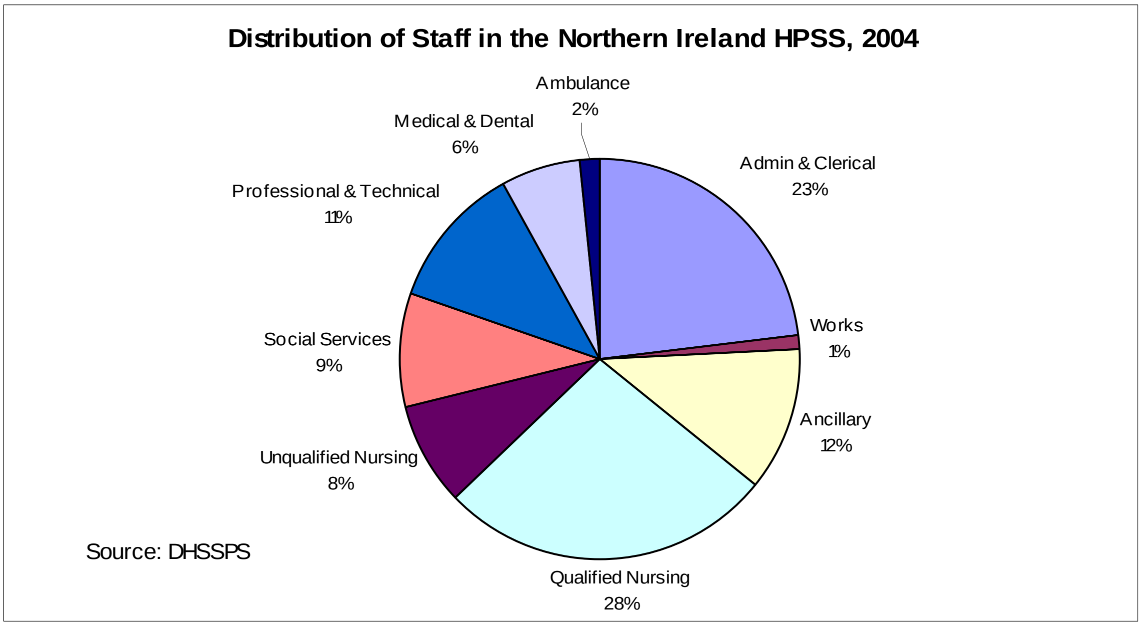
[94] In 2003 Administrative & Clerical staff accounted for 22.8% of Health and Personal Social Services staff in Northern Ireland compared to 14.5% in England.

Figure 3.77: Nurses and administration and clerical staff made up over half of the entire health and social care workforce in 2004.



Source: DHSSPS

3.8.2 Future staffing needs

For England, the Wanless Review projected a need for an additional 62,000 doctors, 108,000 nurses and 74,000 health care assistants over the next 20 years. If these large increases are translated to Northern Ireland, then even allowing for greater staffing now, Northern Ireland will also require a significant increase in staff to provide the same level of service (although given its higher starting point, the increases will not need to be as great). Northern Ireland's share (based on 7% higher level of need) of the Wanless projections would suggest an additional 2,200 doctors, 3,900 nurses and 2,700 health care assistants by 2022. However, taking into account Northern Ireland's higher starting point would suggest an increase of only 2,170 nurses for example[95].

A consistent theme raised by staff representatives in this Review's consultations was the need for better workforce planning. Given that around half of the staff employed in the health and social care sector in Northern Ireland are in regulated professions which require lengthy periods of training, it is essential that there is adequate workforce planning in place to ensure that supply meets demand. It is the role of the department - in conjunction with the local universities - to ensure that sufficient training places are made available in order to meet future staff requirements.

The Needs and Effectiveness Evaluation indicated that health and social care workforce planning in Northern Ireland had been somewhat underdeveloped in the past. In particular, during the 1980s poor planning meant that too many staff were

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[95] The Wanless Projections would suggest that there will be approximately 413,000 nurses in England in 2022, or 7.62 per 1,000 population. Given that there are currently 7.42 nurses per head of population in NI, and adjusting for population change and need, this would suggest an additional 2,170 nurses.

being trained relative to the demand from the health and social care services (which are, in essence, a monopsonist for such labour). In response, during the 1990's there were reductions in the number of training places - with the result that there were perceived to be labour shortages. Whilst there is waste in funding training when there may not be the opportunity to use the skills developed, it is not clear why demand should exactly meet supply for certain public sector professions when it is not the case for most other professions. The additional cost of training is likely to be lower than the premium paid to health care professionals resulting from the tight labour market that has been a feature of the current system.

To improve the standard of workforce planning, in 2001 the DHSSPS commenced a series of uni-professional workforce reviews covering the main groups employed in health and social care - including the main clinical professions.

The main purpose of these workforce reviews was to provide medium term projections of the demand and supply for each profession. The need for staff was expected to increase if increasing health and social care demand were to be met (as a result of an ageing population, changing roles as well as service developments). Supply was expected to fall - due in general to the numbers entering the workforce not being sufficient to balance those leaving. Overall, the workforce reviews projected significant shortfalls in the supply of professional staff by 2006. However, the subsequent *Pay and Workforce Strategy* suggested that the former projections exaggerated the scale of shortfall and that there would be merit in considering the approach to workforce planning in England where there was greater emphasis on policies to ensure that supply met demand (for example, through changes in skill mix, retention policies etc). Whilst the recently produced revised workforce review for nursing has taken on board a number of these criticisms, the approach remains less pro-active than in England[96]. For example, it is assumed when modelling future supply that no progress will be made in reducing the attrition rate from degree courses whilst the anticipated productivity growth is less than in England.

Although there is likely to be a requirement for additional health & social care staff in the coming years, the increase needed may not be as great as that suggested by DHSSPS. Further, it is important to ensure that the existing staff resources are used effectively and efficiently before significantly increasing these inputs.

3.8.3 Effectiveness, efficiency and productivity

It is beyond the scope of this study to consider in great detail the extent to which staff are used effectively and efficiently in Northern Ireland as this would require detailed micro analysis of working patterns. However, as figures 3.60-3.63 in section 3.71 on Efficiency indicated, given that staffing levels are significantly higher than in England, whilst activity levels are slightly lower, this would suggest that productivity could be improved. Figure 3.78 below shows that weighted activity per HCHS employee is 10% lower in Northern Ireland than England. Whilst there are many arguments that could be employed to explain the lower level of productivity in Northern Ireland - such as policy decisions to reduce access times associated with the geography of Northern Ireland, increased health and social care demand arising from high levels

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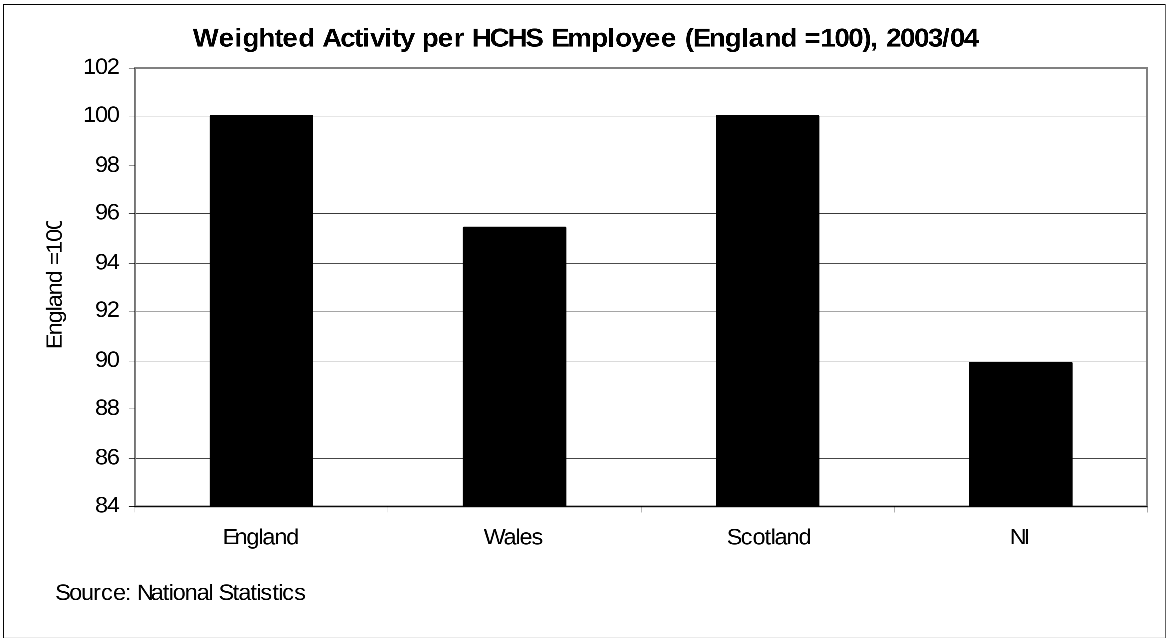
[96] Review of Workforce Planning for Nursing Midwifery and Health Visiting Final Report February 2005, DHSSPS

of deprivation, and poor development of ICT – it is not clear how significant each is in explaining the variation.

Figure 3.78: The level of weighted activity per HCHS Employee is 10% lower than in England, 2003/04.

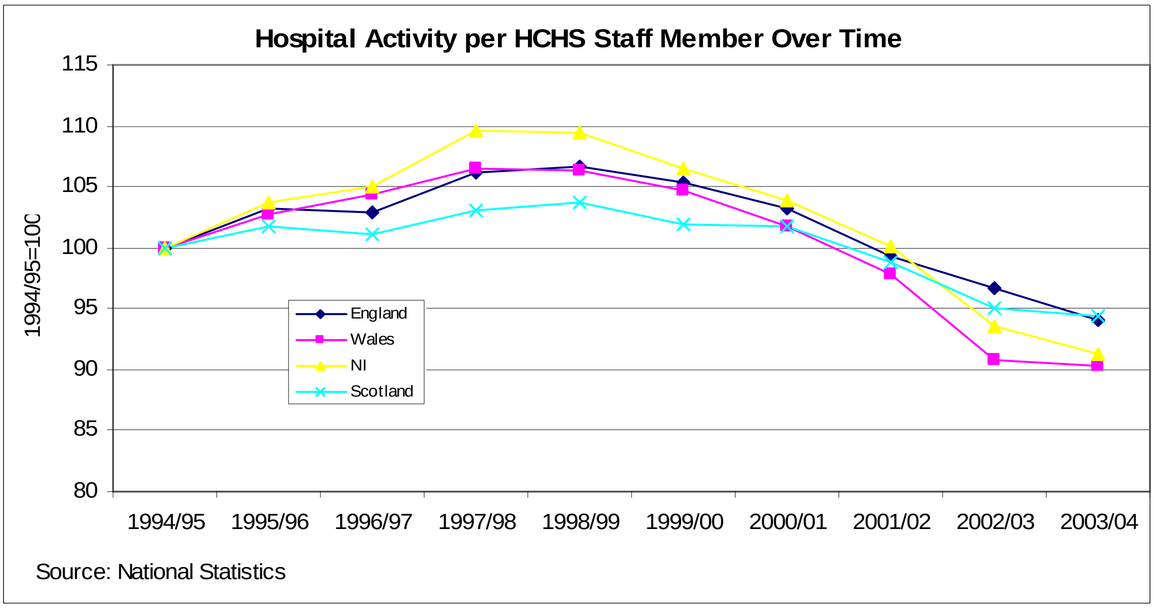


Source: National Statistics

Interestingly, figure 3.79 shows that the productivity of the health & social care sector in Northern Ireland has followed a similar trend to the rest of the UK in recent years. Productivity rose up until 1997/98, since when it has declined as activity has increased at a slower rate than the resources available. Overall, productivity in the health & social care sector has fallen at a faster rate in Northern Ireland than England and Scotland since 1994/95.

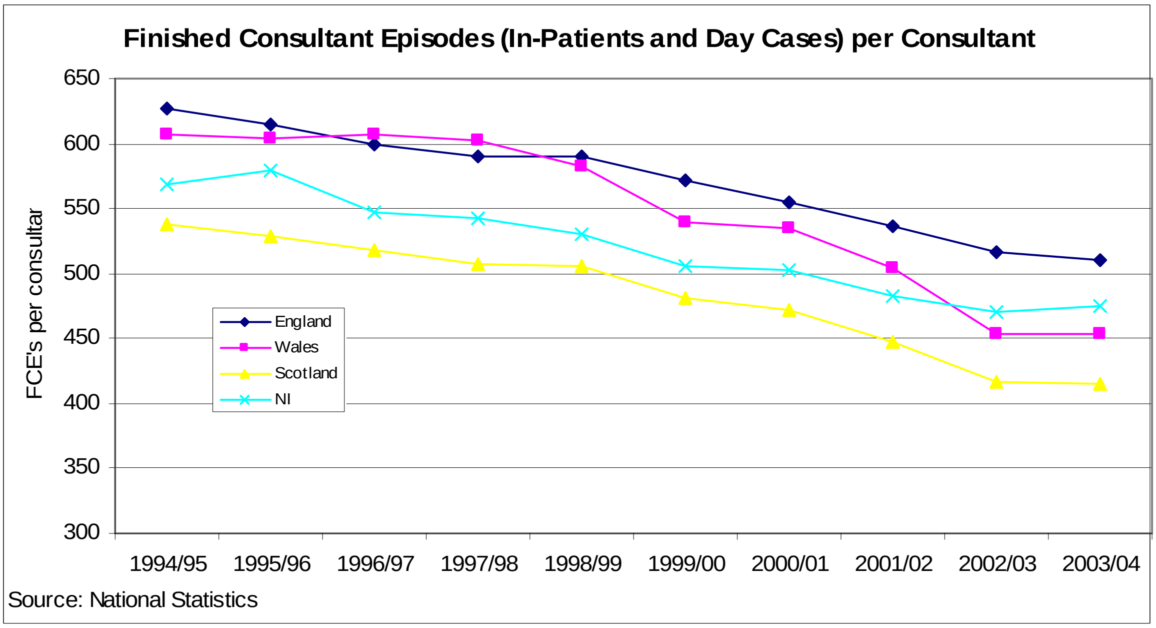
The productivity of consultants, as measured by the number of inpatient and day case finished consultant episode per consultant, follows a slightly different pattern. Figure 3.80 shows that the productivity of consultants was falling before 1997/98. Northern Ireland has experienced the smallest fall throughout the UK in productivity over this period so that the productivity of consultants is higher than in Scotland & Wales but remains (around 7.4%) lower than in England.

Figure 3.79: Northern Ireland has followed a similar trend over time to the rest of the UK in terms of HCHS labour productivity.[97]



Source: National Statistics

Figure 3.80: The number Finished Consultant Episode (In-patients and Day Cases) per consultant is currently higher in Northern Ireland than Scotland & Wales but lower than in England - but trends in all countries have been downward.



Source: National Statistics

The need to improve labour productivity has been recognised. For example, Budget 2005-2008 indicated that £225m out of the £474.2m efficiency savings over the next three years will come from the more productive use of health and social care professionals' time. These savings would fund increases in front line capacity (costing £135m) and the quality of services (costing £90m). However, this Review would note that it is not clear from the information set out in the accompanying Efficiency Technical Notes how the improved service will be achieved. Indeed, the

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[97] Labour Productivity Index is derived by index of total weighted activity (as set out in Figure 3.9) divided by index of NHS employment. Whilst differences in methodology mean that it would not be appropriate to compare levels of productivity the chart is intended to be indicative of general trends.

main activity appears to be the collection of data on performance which, although valuable, in itself will not directly lead to significant improvements.

The Northern Ireland Regional Strategy[98] indicates that productivity improvements in the health & social care sector are expected to come from reduced demarcation; nurses and allied health professionals taking on some of the roles and activity of doctors, and health care assistants taking on some of the roles of nurses. The main focus on implementation revolves around joint aspects of training for medical and nursing staff with the intention of changing behaviours and attitudes towards multi professional working.

The Needs and Effectiveness Evaluation indicated that the level of absenteeism in Northern Ireland Trusts ranged from 3% to 7%, with an estimated overall average of 6% compared to 5% in England. Despite a requirement in Priorities for Action there appears to have been little success in reducing absenteeism rates (which currently range from 4% to 8% for Northern Ireland Trusts compared to an average of 5% for England[99]). This issue was raised as part of the recent nursing workforce review, where the view was expressed that sickness policies need more rigorous enforcement, particularly after maternity leave.

> **Recommendation 21: Further investigation is required of possible reasons for relatively low labour productivity**

3.8.4 Staffing costs

Although movement towards (lower) English staffing levels would result in higher productivity, this could be at the expense of quality of service. An alternative way to improve labour productivity and efficiency is to focus on the costs of staffing.

Health and social care staff in Northern Ireland generally enjoy the same terms and conditions as in the rest of the UK. It was argued in the Needs and Effectiveness Evaluation that this was necessary in order to recruit, retain and motivate staff. In addition, reducing the level of pay relative to the rest of the UK was expected to result in an increase in the number of staff leaving the system- no evidence has been produced to support these arguments.

Pay parity has become more critical in recent years due to the pay reforms initiated in England - such as Agenda for Change for non-medical staff and the new contracts for hospital consultants and general practitioners. These reforms have resulted in substantial increases in salaries, but with the prospect of changes in working practices, higher productivity and improved recruitment and retention of staff. A weakness of these reforms is that the costs are upfront and definitively set whilst the benefits in terms of service delivery tend to be more nebulous and longer term. Given the health and social care funding mechanism for Northern Ireland and a higher level of per capita staffing, implementing equivalent pay reform has placed significant resource pressures on spending in Northern Ireland - as noted earlier in section 2.2.3. Although Northern Ireland has, to date, managed to maintain pay

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[98] *A Healthier Future- A Twenty Year Vision for Health and Wellbeing in Northern Ireland 2005-2025*, DHSSPS

[99] NI figures are for October 03-March 04 whilst England figures are for 2003

parity whilst also maintaining higher staffing levels, recent pay reforms increasingly highlight the opportunity costs of maintaining such a policy.

Pay parity with the rest of the UK has been guaranteed for the past thirty years as a result of provisions in the 1971 Northern Ireland Finance Act, which indicates that the remuneration of persons employed in the health services in Northern Ireland correspond as close as possible with the rates for such services obtaining in Great Britain. In practical terms this has meant that whilst Northern Ireland was not covered under the remit of the relevant national Pay Review Bodies, the recommendations of terms and conditions from these bodies was taken up in Northern Ireland. This policy has continued, with the application of Agenda for Change reforms and changes to doctors' contracts applying equally in Northern Ireland as the rest of the UK. It needs to be recognised, however, that these particular reforms were designed and introduced in response to specific problems in England, problems which may not have occurred to the same extent in Northern Ireland.

Local pay flexibility

In 2003 the Government issued guidance[100] indicating that, within existing national bargaining frameworks, public sector pay should be based on local labour market conditions. In taking this forward, the terms of reference for the national Pay Review Bodies were amended to take into account local factors in their deliberations. Such local labour market conditions include vacancy rates, regional price indices and the pay gap between public and private sectors. Given that Northern Ireland is not covered under the remit of the Pay Review Bodies it is not clear how the Government's policy will be applied with respect to Northern Ireland. However to date there has been little progress in Great Britain, with local pay variations arising mainly in the form of additional payments for high cost areas, whilst the logic of the policy would be to have lower pay levels in low cost areas.

There has been considerable debate as to whether the 1971 Finance Act still implies a statutory requirement to retain pay parity. In particular, it has been argued that the change in policy means that in effect there is no longer a GB-wide settlement for Northern Ireland to retain parity with. However, the local pay policy guidance clearly indicates that national bargaining frameworks will remain. Until there is a break from parity for other regions of the UK, it is likely to be highly controversial to implement such a policy in Northern Ireland. Nevertheless, it is worth reviewing some of the evidence that bears on this issue:

1. Public and private sector earnings gaps

   The 2004 Pay and Workforce Strategy for the Northern Ireland departments set out analysis illustrating that the gap in earnings between the public and private sectors in Northern Ireland was higher than the rest of the UK. Whilst part of the gap could be explained in terms of the security situation in Northern Ireland and occupational structure, a significant differential remained. Figure 3.81, for example, compares the average earnings of Associated Health Professionals

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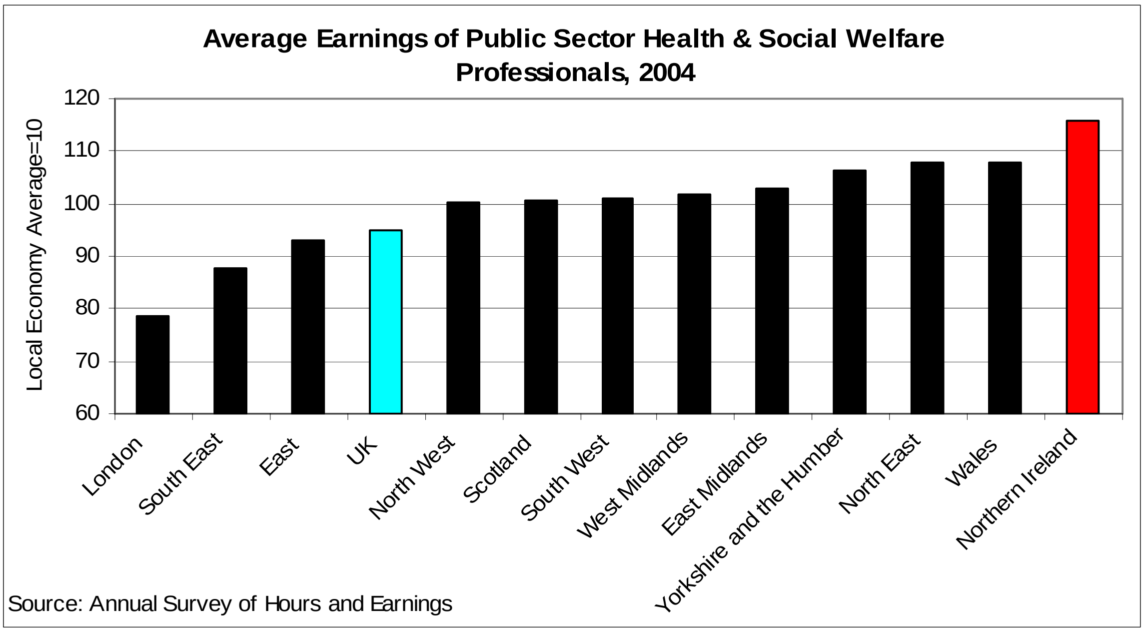
[100] Government Guidance Note on Progressing Local Pay (October 2003), HM Treasury

with the economy average level of earnings for the UK regions[101]. It can be seen that for most UK regions the level of earnings for Associated Health Professionals working in the public sector is higher than the economy wide average. However, the differential is greatest for Northern Ireland, where average earnings are 16% higher than the economy average.

Figure 3.81: Average earnings of Health and Social Welfare Associate Professionals working in the public sector are 16% higher than for the economy as a whole in Northern Ireland.[102]



In terms of specific professions, the 2004 Annual Survey of Hours and Earnings (National Statistics) shows that the average weekly gross pay of female nurses is 23% higher than the average for full-time females as a whole in Northern Ireland whilst the earnings of medical practitioners are almost three times higher than the Northern Ireland average. Although not all people have the appropriate skills to become doctors or nurses it would appear that the health care sector is a relatively attractive career option in the Northern Ireland labour market.

2. Labour migration

One of the main arguments against the break from pay parity is that it would result in significant numbers of staff migrating from Northern Ireland. In particular, most health care staff have transferable skills and might be considered more mobile than the rest of the population. Although it has been suggested that the increase in public sector salaries in the Republic of Ireland in recent years has lead to migration of public sector workers from Northern Ireland, there is little evidence to indicate the such transfers have been significant.

The main movement of staff in the health & social care sector has been from other countries into Northern Ireland. In 2002, approximately 3% of nurses registered in Northern Ireland were from overseas compared to 8% for

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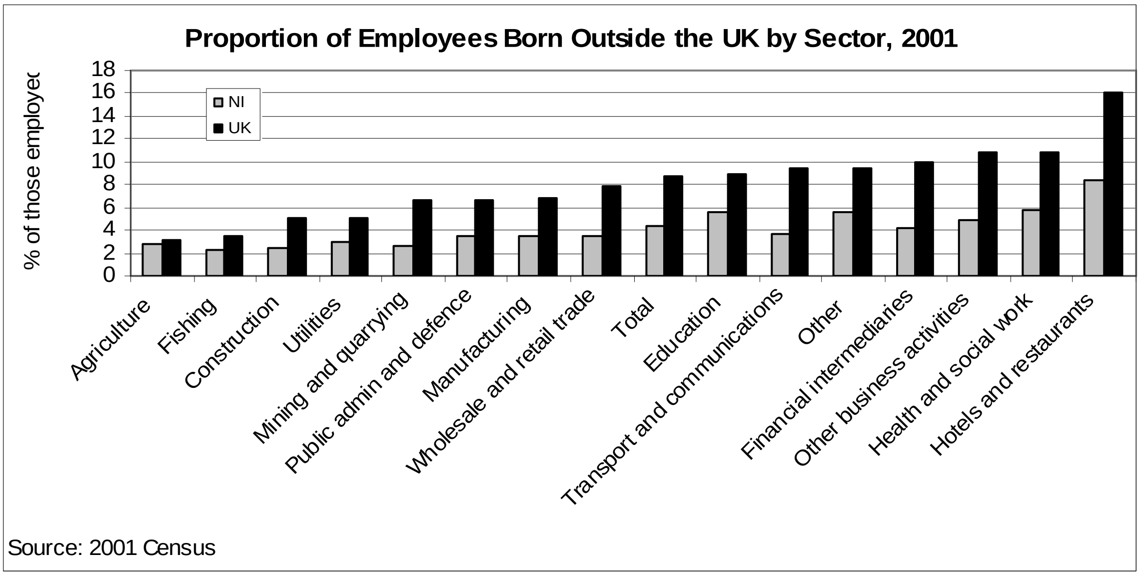
[101] Health and social welfare associated professionals include Nurses, Midwives, Paramedics and Radiographers but exclude Doctors
[102] Average (Mean) gross weekly earnings of full-time employees

England[103]. There are currently 812 nurses from overseas employed by Northern Ireland Health Trusts, equivalent to 5% of nurses compared to over 10% for the UK as a whole[104]. However, there is significant variation between Northern Ireland Trusts with overseas nurses accounting for a higher proportion of the total for the Mater, Royal and Ulster Hospitals.

Figure 3.82: Only 6% of those employed in the Northern Ireland health & social care sector were born outside of the UK compared to 11% for the UK as a whole



Source: 2001 Census

In terms of the overall number of health and social care staff, data from the 2001 Census indicates that 89% were born in Northern Ireland, 4% in England, 3% in the Republic of Ireland and 3% outside the British Isles. Figure 3.82 shows that whist a higher proportion of Northern Ireland health & social care staff were born outside of the UK than the economy average, the share is significantly lower than for the UK as a whole. In addition, the differential is even greater with respect to those born outside of the EU who account for over four times the share of staff in the UK as they do in the Northern Ireland health and social care sector.

Therefore, whilst Northern Ireland has an increasing reliance on overseas staff, this remains to a lesser extent than in the rest of the UK.

3. Pay and cost of living differences

A further argument is that it would be unfair for someone doing the same job in Northern Ireland to be paid less than in England. However, the cost of living is generally lower in Northern Ireland than the rest of the UK with the result that real wages are currently higher in Northern Ireland.

Whilst the 2004 Pay and Workforce Strategy indicated that the cost of living was nearly 10% lower than the UK average, more recent figures for 2004 indicate that prices are only 5% lower in Northern Ireland. Figure 3.83 below shows that the earnings of Associated Health Professionals working in the

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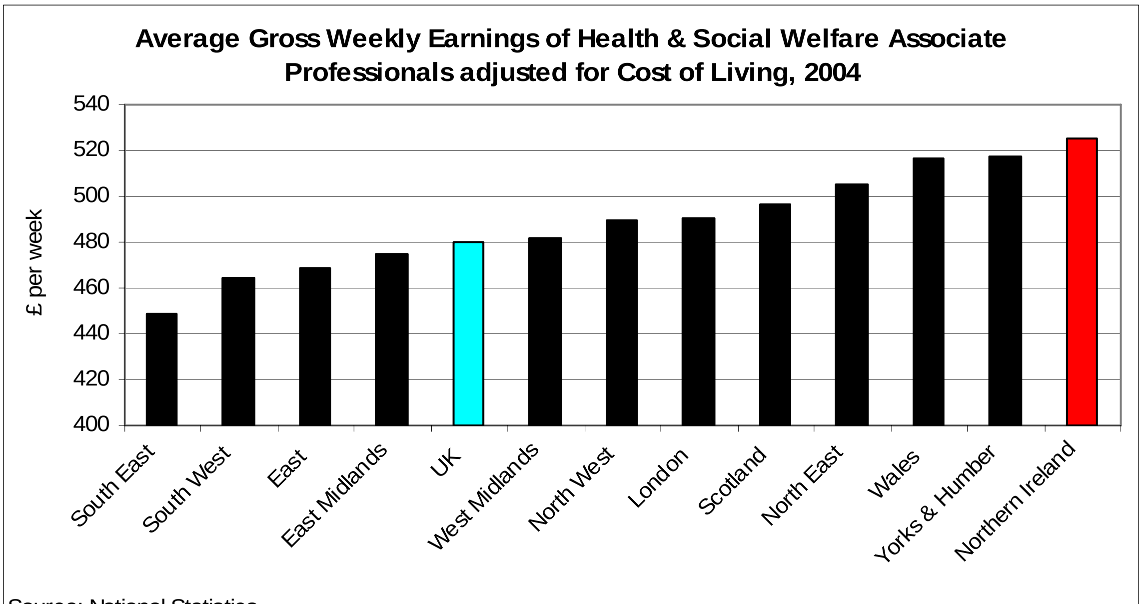
[103] Here to Stay? International Nurses in the UK, RCN

[104] The February 2005 Review of Nursing Workforce Planning indicated that there were 42,000 overseas nurses currently working in the UK.

public sector in Northern Ireland are the highest of UK regions after adjusting for the lower cost of living.

However, these cost of living figures are an average across the whole economy; there are significant variations between income standards due to housing costs. For example, the required income for the lowest income standard is estimated to be 9% lower than the UK average in Northern Ireland, whilst that for the highest is 28% lower[105]. Therefore, for the more mobile health care staff there is likely to be a significant cost advantage from living and working in Northern Ireland relative to the rest of the UK.

Figure 3.83: The Average Gross Weekly Earnings of Health and Social Welfare Associate Professionals Adjusted for Cost of Living is highest of all UK regions



Source: National Statistics

4. Vacancy rates

Whilst there are a number of complications in comparing vacancy rates for health care staff across UK countries, Table 3.5 provides a broad comparison.

Overall vacancy rates in Northern Ireland are lower than England and Wales - in particular, for nursing and medical & dental staff[106]. Significant progress has been made in reducing vacancies in recent years in part due to significant recruitment of overseas doctors and nurses.

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[105] Figures from Croner Reward Cost of Living Regional Comparisons March 2004

[106] More recent figures from the Nursing Workforce Review suggest that the 3 month vacancy rate for nurses rose to 1.5% in Northern Ireland in 2004.

Table 3.5: 3-month vacancy rates in Health Service for England, Wales and NI

Category	**NI (Jun 04)**	**Wales (Mar. 04)**	**England (Mar. 04)**
Medical and Dental of which consultant[107]	1.9 *3.2*	7.9 *8.8*	4.3 *4.4*
Nursing, Midwifery and Health Visiting	1.4	2.1	2.6
Social Services	0.9	N/a	N/a
Admin and Clerical	0.6	N/a	N/a
Professional and Technical	1.8	2.4	3.4
Other	0.9	1.4	1.3
All Staff excluding Social Services	1.3	2.1	2.2

Source: DHSSPS, NHS, NAW

5. Labour supply and training

The picture in terms of recruitment is slightly more confusing, as the recruitment procedure begins when the choice is made for degree course. Figure 3.84 shows that the number of applicants per acceptance for degree courses for Professions Allied to Medicine was higher than that for the rest of the UK[108]. However, the ratio for medicine & dentistry courses at Northern Irish institutions was significantly lower than the rest of the UK[109]. This latter ratio of around 3:1 is not viewed by DHSSPS as being particularly low and the view from the consultation process was that recruitment was not a significant problem.

A possible reason for the lower ratio might be that Northern Irish students are selecting not to go into medicine because of the higher qualifications requirements. As a broad indication of this, 94% of successful Northern Irish applicants to medicine & dentistry degree courses had the equivalent of three ‘A’ Level passes at A grade or better, compared with 84% for the UK as a whole[110].

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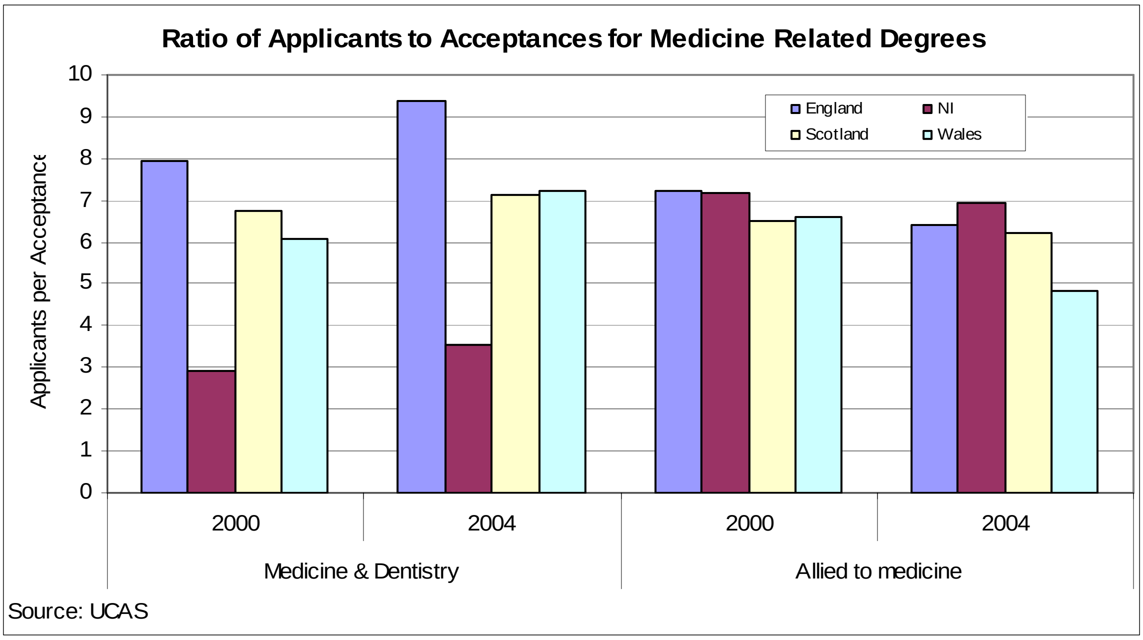
[107] Consultant data is for September 2003. DHSSPS have indicated that the rate is now in the region of 7%.

[108] There was some variation between the professions allied to medicine with Nursing (2.85) having a lower ratio than Physiotherapy (7.89), Dietetics (6.11), Occupational Therapy (7.10), Podiatry (7.07), Radiography (7.23) and Speech & Language Therapy (12.87)

[109] For Medicine alone the ratio was 3.73:1

[110] In terms of Allied to Medicine Degree Course which includes Nursing, Ophthalmics and Pharmacology the percentages were 35.2% for NI and 23.7% for the UK.

Figure 3.84: The Ratio of Applicants to Acceptances for Medicine Related Degree Courses is lower in Northern Ireland than the rest of the UK



Source: UCAS

6. General Labour Market Conditions

In terms of more general indicators of the public sector labour market. whilst there is a paucity of comparable data for the UK regions, the available evidence would tend to suggest that there is greater availability of labour for the Northern Ireland health and social care sector than the rest of the UK. Although unemployment has fallen towards the UK average, the employment rate remains the lowest in the UK, whilst Northern Irish schools are producing significant numbers of highly educated young people, suggesting that there is a greater potential supply of labour in Northern Ireland than the rest of the UK. Recruitment and retention issues are not likely to be more problematic in Northern Ireland than elsewhere, therefore.

Conclusion

Relative to England, the health & social care sector in Northern Ireland currently has a reasonable level of staffing capacity. Whilst Northern Ireland will require greater numbers of health care staff in the coming years, there is scope for using existing resources more effectively.

In looking to the future, an important issue, however, is whether Northern Ireland should continue to bear the opportunity costs of maintaining pay parity with the rest of the UK - particularly as the current system of public sector funding will make it increasingly difficult to both maintain parity and, for example, continue with higher staffing levels than elsewhere

Whilst there is scope for work patterns to be more efficient, there is also potential to more closely align the levels of pay for health & social care staff with local labour market conditions (within existing national frameworks) without damaging the ability of the services to recruit and retain appropriate staff. Clearly, the issue of pay parity is sensitive, and it will be the case that any policy designed to tackle this will in turn need to be sensitive to staff morale and motivation; it may well be the case that for many professions in the services that it would be better to retain pay parity and that further, where, in the best interests of the system as a whole, parity is not retained, that alternative, non-financial benefits could be considered. However, from our consultations and consideration of the available evidence, there is a strong case that the main reason for past and predicted labour shortages has been an insufficient number of training places rather than the level of pay per se.

> **Recommendation 22: Health and social care workers in Northern Ireland should formally come under the remit of the relevant GB Pay Review Bodies: this will enable the Government's local pay policy to be implemented on an equal basis in Northern Ireland to the rest of the UK.**

4. Performance management

4.1 Introduction

The previous section has shown that on broad efficiency measures, and in particular in terms of waiting times, there is room to improve the performance of Northern Ireland's health and social care system.

Northern Ireland is not alone. As the OECD have noted[111], almost regardless of funding levels or sources, health and social care systems around the world face common issues and problems when it comes to improving their performance. Despite high levels of commitment and professionalism from health and social care staff, best efforts to provide appropriate care in the most efficient way can be frustrated by the way systems are structured and organised. Poorly designed (or, indeed, the complete absence of) incentives and systems to promote improvements in performance at national, local and individual levels can significantly affect the way the health and social care system responds - to patients' needs, to the dynamic nature of medical technology and to changes in attitudes and values.

How health and social care systems are managed, the incentives and sanctions in place and the type and availability of performance information are critical to improving performance.

In order to set some context for the situation in Northern Ireland with respect to performance management this section first details some of the reform efforts being pursued in OECD countries. It then describes the current performance management system in Northern Ireland and recent suggestions for changes (mainly in structures) aimed in part at improving performance.

The key question this section addresses is whether current reforms and modernisation in Northern Ireland will be adequate to tackle the performance issues previously identified.

Section Conclusions

Current performance management arrangements lack the performance structures, information and clear and effective incentives - rewards and sanctions - at individual, local and national organisational levels - required to encourage innovation and change.

These criticisms were confirmed in our consultations with key stakeholders. It was clear, for example, that the current performance management system was adjudged to require further development, to deal with an absence of accountability in the system. This review does not feel that recommendations of the Review of Public Administration adequately addresses the weaknesses with the performance management system. And contrary to the RPA, this Review would suggest that some form of separation between the providers of services

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[111] OECD (2004) Towards high performing health systems. OECD, Paris.

and the funders/commissioners of services would be an important factor in sharpening up incentives in the system.

Overall, the system needs to be reformed to take on serious, long term central target setting coupled with rewards and sanctions at organisational and individual levels and greater devolution to providers to give them the scope to respond. In turn, providers themselves need to consider how to devolve functions within their organisations, in particular, ways in which to engage frontline staff with the incentives faced by the organisation as a whole - through, for example, devolution of budgets and associated responsibilities.

The nature of the rewards and sanctions need careful thought. For example, mainly for reasons of scale (and efficiency), the competitive economic environment currently being developed in England is unlikely to be appropriate in Northern Ireland. However, this does not rule out, for example, the introduction of an activity-based prospective reimbursement system for providers (similar to Payment by Results) with tariff setting (not necessarily fixed at average costs) used to drive improvements in efficiency and selective increases in activity to meet pan-service goals. Nor does it rule out the promotion of greater public and patient awareness of variations in performance in the system.

Moreover, it does not rule out careful expansion of patient choice. While in England choice is being rolled out mainly with a policy emphasis on the leverage it may have over providers (crudely, losing business will stimulate cost and quality improvements), from the patient’s point of view, a more formalised and embedded process of choice (not just of hospital, but over the myriad of decisions that are taken throughout the system which affect a patient’s care) can improve patient satisfaction and service responsiveness. This may be a weaker incentive than that being introduced in England, but the limits to what could realistically offered by way of choice need to be recognised in what is a relatively small system. Nevertheless, there may be certain services, specialties, operations etc where options do exist for real patient choice and where patients would like to exercise greater choice.

In addition, and despite the previous rejection of GP fundholding, to both strengthen the involvement of general practitioners in the system and as part of a devolution strategy for commissioning secondary care services, thought should be given to the practical involvement of GPs in the purchasing of care. Again, Northern Ireland has an opportunity to develop its own approach to this form of devolved commissioning.

Finally, no system relies on just one or two performance levers. In England, for example, the new payment system and (managed) patient choice are going to run alongside continued use of targets (renamed ‘standards’) and, importantly, an evolving regulatory system at arms length from government which aims to promote the ultimate goals of the system - better quality of care, more efficient and cost effective use of resources. NICE, the National Patients Safety Agency, the Healthcare Commission etc, are important organisations which aim to promote better care. Much of these organisations’ work and output are public goods available for any system to use and from which Northern Ireland could benefit and could inform development of the new HPSS Regulation and Improvement Authority.

4.2: Health care reform in OECD countries

Reducing costs, improving clinical and cost effectiveness, increasing public health, patient safety and patient responsiveness have been key issues for most OECD countries for more than two decades. Tactics and strategies to improve performance have drawn on economic, management and organisational theory as well as the results of experiments in many countries. The OECD have identified over twenty (at least) different areas where reform has or is being tried in order to tackle three broad performance concerns: Improving public health and clinical quality; Improving system responsiveness; and Improving efficiency and cost effectiveness.

Box 4.1 summarises the various reform strategies identified by the OECD; while not all of these are of relevance or applicability to the health and social care system in Northern Ireland, this list provides some structure in describing Northern Ireland's current performance management system and efforts to reform and modernise. It also illustrates the sheer range of possible reform tactics that could be considered in the Northern Ireland context.

Box 4.1: Reform strategies to improve performance

Improving public health and clinical quality

- Focused public health programmes
- New health care delivery arrangements
- Patient safety systems
- Public reporting of information on quality
- Targets and standards for improvement
- Technical assistance to improve quality and performance
- Aligning economic incentives with effectiveness incentives

Improving system responsiveness

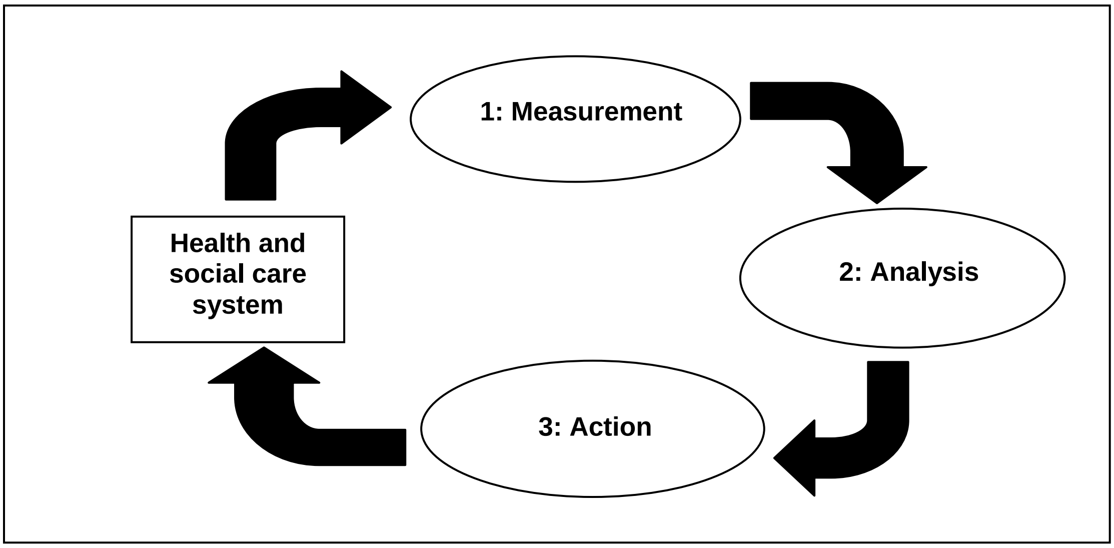
- Improving patients' rights to treatment
- Patient satisfaction and experience surveys
- Patient choice

Improving efficiency and cost effectiveness

- Control of wages and prices
- Budgetary caps
- Shifting costs to the private sector
- Shifting care to lower cost services within the system
- Incentives embodied in primary care provider payments
- Incentives embodied in secondary care provider payments
- Separation of purchasers and providers
- 'Earned autonomy' for providers
- Provider competition
- Assessing technological change
- Pharmaceutical regulation

Within the continuous performance management cycle (see figure 4.1), the majority of reform strategies pursued in OECD countries have focussed on the third performance management activity, *actions*. However, as noted later, of equal importance with respect to Northern Ireland are the prior stages of measurement and analysis (for example, key areas of performance are poorly described in official statistics and hence the reasons why changes in performance measures occur poorly understood).

Figure 4.1: The Performance Management Cycle



Drawing conclusions from the range of reform activity being pursued in OECD countries is difficult. However, some common strategies emerge which might be helpful in informing possible changes to the performance management system currently in operation in Northern Ireland:

- separate purchaser and provider functions,
- better align incentives with objectives through contracts,
- decentralise decision making,
- increase competition/contestability among providers
- benchmark performance against best-performing providers,
- use (carefully designed and run) output-related prospective payment systems

The OECD suggest that,

> *'While the positive impact of such policies has most often been weakened by continued central control, tight spending limits and tighter supply constraints than elsewhere, these policies generally have been sustained, despite subsequent reforms in many countries.*[112]

But the OECD go on to caution that,

> *'Experiments with competition among providers have been less successful and reforms have been reversed in those countries where they were*

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[112] OECD, *ibid*

> *introduced. Failures partly reflected tight supply conditions and monopoly positions of providers in local health-care markets and lack of sufficiently skilled purchasers. Positive results from competition probably require establishing market conditions conducive to competition, better purchasing capacity, and the information base needed to appropriately set and monitor contracts.'*

Reform and modernisation are, then, the norm rather than the exception in health and social care systems around the world. While there are few definitive explanations for observed successes and failures in different countries' reform strategies, in the face of clear evidence that systems are not achieving the best results given resource levels and the particular economic, social and other circumstances in which they operate, doing nothing is not an option.

Next we review current arrangements for performance management in Northern Ireland and, with reference to some of the reform strategies pursued elsewhere, suggest possible options for change.

4.3 Current performance management arrangements in Northern Ireland

Performance management systems are, in reality (and despite the simplified three-stage process described in figure 4.1) rather complex, and invariably difficult to describe. However, at a very broad level of description, the current performance management system in Northern Ireland could be characterised as centrally-driven within a hierarchically-managed organisation. However, the system lacks appropriate performance structures, information and clear and effective incentives - rewards and sanctions - at individual, local and national organisational levels to encourage innovation and change.

These criticisms emerged from our consultations with key stakeholders. It was clear, for example, that the current performance management system was adjudged to require further development, with an absence of accountability in the system. In particular, none of the individuals and groups we met were able to provide a clear description of the incentives and sanctions in place to ensure that the targets set by the Minister were achieved.

The general view was the system would benefit from less centralisation of control whilst it was unclear whether the Department or the Boards were in control of the Trusts. The view of DHSSPS officials was that the ‘hard line’ approach to performance management in England over the last few years had lead to disruption, uncertainty and a lack of confidence amongst management and hence would be inappropriate in Northern Ireland. Nevertheless, an internal DHSSPS/HPSS review of the current performance management system completed in January 2005 was critical of the system and has recommended various changes[113] (see Box 4.2), However, none of its recommendations address the key issue of *how* performance is to be improved.

Box 4.2: DHSSPS/HPSS review of current performance management system

A review of the performance management arrangements for the HPSS was concluded in January 2005 and concluded that the current system:

- is complex, unwieldy and very bureaucratic;
- not comprehensive in terms of being able to measure HPSS performance as a whole, often focusing on new initiatives rather than the totality of resources;
- lacks linkage between annual and strategic plans. As a result, there is a lack of continuity between the two and often a focus on short-term gains at the expense of longer-term achievements;

And that,

- targets do not always reflect the real priorities, particularly in terms of the outcomes for people who use the health and social services;
- data is often collected which is not put to any useful purpose; and
- equally, appropriate information is often not available to support the monitoring process.

The review recommended various changes - chiefly, a new set of performance indicators to capture the totality of the work carried out by the HPSS.

However, the review contained no criticisms or recommendations about the *effectiveness* of the current system to actually improve performance - in particular, no reference was made as to the process or mechanics by which performance is to be improved.

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[113] HPSS Performance Assessment and Reporting Framework, Report and Proposals from Working Group, DHSSPS).

Below we examine this particular issue and other key elements of a performance management system - structures and processes, information and analysis, and standard/target setting.

4.3.1 Performance structures and processes

By performance structures we mean leadership, management and accountability arrangements in the health and social care system. In this respect, the Review of Public Administration (RPA)[114] has tackled a different aspect of performance structures and has made proposals for changing the number of health and social care organisations. However, the RPA's recommendations - drafted by the DHSSPS - also suggest a mode of working and interaction between health and social care organisations which touches on the way performance management systems might develop. In particular, the RPA rejects a competitive model in health and social care, and instead proposes an integrated commissioner/provider model. We pick up this issue in the conclusions to this section.

Pace the current recommendations of the RPA, the health and social care performance management system, as noted above, is centralised and hierarchical in nature; over 1,000 staff at the DHSSPS[115] and a further 800 staff in the four Boards control the flow of funding to service providers, develop and promulgate planning and strategy guidance and set performance goals - primarily through the annual Priorities for Action (PfA) document.

The DHSSPS develop the annual PfA based on their Public Service Agreement (PSA). Boards then respond with Health and Wellbeing Investment Plans (HWIPs) which set out how they will meet the PSA goals. Finally, individual trusts then have to produce Trust Delivery Plans (TDPs) which in turn set out how they will use their resources in pursuit of these goals.

In terms of monitoring and accountability for meeting PfA plans, as the 2004/5 PfA states,

> *'HWIPs and TDPs will continue to provide the focus for rigorous [Health and Personal Social Services] monitoring and accountability arrangements throughout the year. These arrangements include quarterly reporting to the Department by Boards and Trusts, meetings between Boards and Trust officials and the Department[116] and accountability review meetings involving Board chairs and the Minister.'[117]*

In effect, the Department runs the health and social care services in Northern Ireland along fairly traditional management lines and with accountability flowing upwards from trusts, to Boards, and finally to the Department. As is clear from descriptions of the performance management system supplied by DHSPSS to the review (see

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[114] An interim report is currently (May 2005) out for consultation

[115] DHSSPS have indicated that over 400 of these officials are providing direct operational services.

[116] Extracts from annual DHSPSS/Board accountability reviews are noted in Annex I.

[117] It is worth mentioning in passing that while it is fairly easy for members of the public to locate publications setting out DHSSPS, Board and Trust plans, priorities and targets for the following year, it is much harder to locate any publications succinctly summarising what targets had been achieved in previous years.

annex H), there is little account of how failure to meet targets or plans is dealt with and little on positive mechanisms and processes to encourage improvements in performance.

From our consultations, it was clear - as noted above - that this system is generally considered to be too centralised, too bureaucratic, and with a lack of clarity as to whom should be held responsible for performance improvement.

From our survey of chief executives of trusts and in relation specifically to the DHSPSS waiting time performance management arrangements and the role of incentives to meet targets, there was a split between those that felt current DHSPSS waiting time performance management arrangements were effective, and those that felt that they were either not very effective or ineffective (see table 4.1).

Table 4.1: Trust chief executive survey: 'How effective are the Department's external waiting time performance management arrangements?'

The Department's waiting time performance management arrangements are…	Number of responses
Very effective	0
Effective	10
Not very effective	3
Ineffective	3
It is too soon to comment	2

While there seems to be some contentment among chief executives regarding the effectiveness of a system that is meant to improve the performance of organisations they manage, we would observe that the outcome of this system with respect to waiting times does not appear to have produced significant improvements (see section 3.6 on waiting times).

We therefore suggest that serious consideration be given to ways to improve the structures governing the performance management system and the processes used to lever up performance.

4.3.2 Performance information and analysis

Any performance management system, whether hierarchical and management driven, or decentralised and driven through downwardly accountable mechanisms, requires timely and appropriate performance information on which to base future decisions and monitor the outcomes of past decisions.

The experience of this Review in its own attempts to draw together and analyse performance information confirms the DHSSPS/HPSS' s own review of the performance management system that the right information does not always exist or that information systems sometimes lack the ability to provide answers to basic performance questions. Asking, for example, a straightforward question such as whether or not waiting times targets had been met from year to year proved more difficult for this Review to clearly establish than should be the case[118]. And while the

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[118] With current information systems, as the NI Audit Office have noted (*Waiting for Treatment in Hospitals*, NIAO, November 2004), it is impossible to know how long individual patients wait from GP

Review has presented various perspectives on tracking funds through the system, this was by no means easy or, indeed, directly addressed key performance questions concerning the benefits derived from recent spending increases.

But more than the collection of the right sort of information, there is the question of engaging in the right (or indeed, any) analysis of data to address performance problems and issues. For example, as far as this Review has been able to ascertain there has been little or no thorough analysis in or outside the DHSSPS of reasons why A&E attendance rates in Northern Ireland are so high (around 31%[119] higher than in England for example). Similarly, there is little or no analysis of the equally high rate of GP consultations, whether these are appropriate or indeed desirable from a clinical point of view (or indeed whether best use is being made of a valuable and expensive health care resource).

Finally, information on performance is not given the public prominence it deserves. As already noted elsewhere in this Review, performance information has been seen as part of the remit of the statistics section of the DHSSPS and by implication (and in practice) separate from the performance analysis/management system and somewhat buried from public view.

4.3.3 Standard/target setting

While the annual Priorities for Action documents have nominally set out goals and targets each year, as this Review noted with respect to waiting lists and times, the PfAs appear somewhat short term, with little connection across years or clear long term goals and appropriate targets. There is an overwhelming case in Northern Ireland for a new look at systematically setting short, medium and long term objectives and quantifiable standards/targets for the health and social care system.

There are clear dangers inherent in an over-reliance on targets as part of a performance management system, but in the (desirable) absence of a market-driven process, targets can act as the ‘signals’ to providers, helping to direct their priorities and energies into those areas, services and outcomes deemed desirable.

This, however, begs the question of what *is* desirable. The use of targets places a significant onus and responsibility on those setting the targets to balance, for example, the needs of individual patients or clients against those of the community as a whole; or to reach a balance in the often inevitable trade offs between desirable goals such as efficiency and equity. On this, there is a clear need for each ‘level’ in the system to be clear as to its role and responsibility with regard to the generality or specificity of targets. Overall strategy and priorities need to be set by government, with the DHSSPS translating these into more detailed targets.

4.3.4 Incentives: Rewards and sanctions

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referral to inpatient admission. Moreover, the lack of a patient record-based information system (such as the Hospital Episode Statistics system in operation in England for over a decade) at NI level also makes it virtually impossible to know waiting times for specific procedures.

[119] Provisional figures for 2004/05 indicate that the gap has fallen to 28%.

Targets are necessary, but not sufficient for improving performance, however. Of absolutely crucial importance is the system of incentives and sanctions associated with targets. The 2002 Wanless Review made some important observations about the role of incentives and sanctions in driving up performance in health and social care.

In particular, the review noted that:

> *'Appropriate processes must be in place to ensure that the nationally-set standards are delivered by the health service. There are many cases where this has not happened and standards of care delivered have fallen short. The vision of the health service in 20 years' time set out in this Report cannot permit this, so the processes of objective setting, incentivisation and targeting have to be sensitively designed to ensure they achieve the required results rather than distort resource allocation.*
>
> *There are a number of aspects to such 'processes'. They particularly relate to the way in which resources and information flow around the system and in which incentives and targets are used to direct the delivery of efficient and effective levels of care. The flows are vertical, between those setting standards nationally and those delivering them locally, and horizontal, between the different health and social care providers locally.*
>
> *There is a fine balance to be struck in deciding on the most appropriate way to ensure that central standards are achieved across the service. The setting and auditing of targets is one means which can be used. Financial incentives are another.' (Para's 6.23-6.25 Securing our Future Health: Taking a Long-Term View,* HMT 2002*)*

This Review agrees with these observations, and in particular with the need to design open and explicit incentive systems which reward success and penalise failure. A survey this Review conducted among trust chief executives to explore issues concerning waiting times performance revealed - at best - some ambivalence towards the current performance management system.

For example, just over half of chief executives stated that current performance management arrangements provided little or no incentives for their trusts to meet waiting times targets and just five out of sixteen that it provided sanctions if trusts fail to meet targets (see table 4.2). There was agreement that to some extent performance management arrangements would be more effective if they included stronger incentives and sanctions. The very fact that there appears to be disagreement between chief executives over whether the current system contains any incentives or sanctions at all is problematic, and suggests greater clarity and a shared understanding of the performance management system is needed.

Table 4.2: Trust chief executive survey: ‘To what extent are there incentive for your trust to meet waiting times targets, and sanctions if you miss them?’

	Performance management arrangements provide **incentives** for the Trust to meet its waiting time targets…	Performance management arrangements provide **sanctions** if the Trust fails to meet its waiting time targets…	Performance management arrangements would be more effective if they included **stronger** incentives and sanctions for achieving waiting time targets
To a large extent	**2**	**1**	**2**
To some extent	**6**	**4**	**8**
To a small extent	**5**	**6**	**4**
Not at all	**4**	**5**	**1**

And for those chief executives who believed more incentives and sanctions were needed table 4.3 outlines their responses.

Table 4.3: Trust chief executive survey: ‘What incentives and sanctions would be most effective in improving waiting time performance?’

Rewards	**Sanctions**
Rewards of investment funds to divisions	No service development for poor performing departments
Improved flexibility in being able to reward key individuals not covered by performance related bonus system	No staff development for poorly performing departments
Transfer services to departments which have good performance records and have genuine competition	Increased organisational and individual accountability for failure
Increase funding available for exceeding target	Money follows the patient reimbursement
Productivity payments for staff	‘P45s’ for failing managers and practitioners
Small amounts of funding to purchase equipment	League tables. Funding related to performance.
First priority for additional operating sessions	
Money follows the patient reimbursement	
Investment linked to performance	
League tables. Funding related to performance.	

These suggestions prompt a number of possible ways forward for addressing some of the deficits in the current performance management system identified above and noted by many of those we consulted during this Review.

Tariff-based provider budget setting/payment system

Healthcare Resource Group (HRG)-based reference costs form the basis for the reform of hospital reimbursement system (Payment by Results, PbR) in England. Although linked with patient choice (and money following the patient), a key independent aspect of PbR and one which embodies a powerful financial incentive to reduce variations in costs (and, over time, to drive down the mean) is the fact that individual HRG ‘prices’ are fixed. In England, and for the time being, HRG tariffs are fixed at the national average HRG cost. The implication of this is that hospitals providing HRGs at above-tariff cost will need to examine ways of reducing their costs.

Such a payment system could be used as a budget setting system for trusts, one which directly links reimbursement to activity and which, through the tariff setting process, embodies a direct incentive to address cost variations.

‘Earned autonomy’

The reward from earned autonomy can be a combination of greater freedom from central control and diktat (earned on the basis of achieving goals set centrally) and access to financial rewards - for example, specific performance-related funding.

Patient choice

From the patient’s point of view, a more formalised and embedded process of choice (not just of hospital, but over the myriad of decisions that are taken throughout the system which affect a patient’s care) can improve patient satisfaction and service responsiveness. Moreover, choice based on more explicit information on performance - for example, waiting times - can help reduce performance variations.

GP commissioning

Although previously rejected, the idea of devolving the purchasing or commissioning of patient secondary care to general practice could provide an additional stimulus for secondary care providers to more actively respond to the concerns GPs have about the care their patients receive. The survey of GPs conducted by this Review to explore views on waiting lists and times produced some strong responses from GPs who often felt that the secondary care system was not always doing all it could to meet the access needs of their patients (see Annex G).

GP commissioning does not have to follow the model of fundholding in terms of, for example, the volume of services GPs commission. Commissioning could, for example, be based around specific services, specialties or even interventions.

The objective or focus would be to sharpen the incentives on the secondary care provider side to respond appropriately to the signals GPs would send as a result of the pattern of their commissioning.

Publishing performance information

The publication of performance information is not only a necessary aspect of public accountability, but can also provide information to inform patients' choices within the health and social care systems, make a public link between spending and outcomes, and highlight progress towards targets. Wide and prominent dissemination of performance information can also improve the quality and timeliness of information[120].

An independent inspectorate (see below) may consider publishing an annual overview performance report on the health and social care system which would collate all targets and associated information and reach an overall judgement on progress. Such assessments need to be seen to be independent and not feel obliged to pull their punches: It needs to be recognised that publishing performance information is not (and should not be) a comfortable thing for the health and social care system.

External support and advice

Support from an external source or agency can often help individual organisations successfully tackle performance problems and can act as a way to disseminate learning and new ways of doing things across the health and social care system. Support may be delivered in a formal way via some specific organisation (such as the Modernisation Agency) and as the result of a specific trigger (failure to meet a target or satisfy a regulatory inspection) or could be informally arranged and provided by another trust.

Independent inspection/regulation

Ensuring that the health and social care system not only reaches minimum standards of quality of care and minimises risk to patients, but also strives for improvements in quality can be enhanced through independent inspection and regulation. The newly established HPSS Regulation and Improvement Authority in Northern Ireland is currently developing ideas for its role and activities, but it could usefully examine the development of similar organisations (such as the former Commission for Health Improvement, now the Healthcare Commission in England). It could also explore the possibility of more formal connections to exploit economies of scale.

This Review has not had the time to work up how any or all of these options for injecting a greater sense of urgency and 'bite' into the performance management system might be developed in the context of Northern Ireland. By way of comparison, and to some extent evidence of what works and what does not, Box 4.3

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[120] Currently, performance information is not only buried in the Statistics and Research section of the DHSSPS website, but is limited in scope and extremely user-unfriendly.

summarises the recent experience of developments in the English NHS performance management system.

Box 4.3: Recent experience of developments in the English NHS performance management system: there is no 'magic bullet'.

Over the last five years or so the English NHS has been subject to a barrage of changes in its performance management system in attempts to lever up performance and, in particular, to ensure that Ministerial and government commitments were met.

Between 1997 and 1999, the main focus of health policy was to explore alternative arrangements to the internal market which, in their 1997 manifesto, new Labour had promised to abolish. In place of fundholding, for example, GPs were offered influence via newly reformed health authorities - Primary Care Groups. Importantly, targets - and one target in particular, Labour's manifesto pledge to reduce waiting lists by 100,000 - emerged as a tool of performance management.

Ministerial changes, a commitment to large increases in funding and a perception that the new arrangements were not delivering change fast enough, lead to the drawing up of the NHS Plan in 2000 and a tougher, more centralist system and experiments in rewards and sanctions in relation to an expanded set of longer term targets. Franchising of top management, national performance funds, greater public dissemination of performance ratings ('naming and shaming') and star ratings emerged to increase pressure on the system to deliver.

And overall, the period from 2000 to 2004 was a time which saw remarkable reductions in waiting times and the achievement of other targets set by government. There were also costs. Complaints about micro management by Ministers, the distortion in clinical priorities arising from tactics to meet stringent targets and some evidence of managerial manipulation of performance data became more common. In part (although the NHS Plan flagged this next stage in the development of the performance system) this lead to greater emphasis on 'earned autonomy' - that is, less central interference earned by meeting targets. The creation of Foundation Trusts status embodied this devolutionary shift.

From 2004, the system entered a new phase - greater devolution, but also increased independent monitoring and regulation and the start of experiments in patient choice. Importantly, a new reimbursement system for hospitals began its phased implementation - Payment by Results. This system will not only enable money to follow the choices made by patients, but due to its fixed tariff, provides a very strong financial incentive on above-tariff trusts to reduce their costs. Despite this search for more 'automatic' or devolved mechanisms for levering up performance, the system still retains some tough targets - notably the goal of reducing maximum waiting times from GP referral to hospital admission to 18 weeks.

The current focus of policy is now on purchasing. Primary Care Trusts (formerly Primary Care Groups) have generally been felt not to have performed well, and experiments are now taking place with a form of GP fundholding - GP commissioning - as a possible way of sharpening the purchasing function.

Much in the system is still evolving and drawing hard conclusions about what works and what does not - or rather, what works, but at what cost - is difficult. However, the health system overall has probably learnt the habit of change and has gained a greater confidence in experimenting with new ways of doing things. Importantly, it has also learned the benefits of clinical engagement in the process of change (through, for example, the development of the national service frameworks, and clinical networks).

Given the record on recent and current progress on improving system performance in Northern Ireland, doing nothing would not appear to be an option and ways need to be explored for introducing some 'constructive discomfort' into the system alongside greater devolution of responsibility and increased independence from government of some functions such as inspection and performance monitoring and reporting to government and the public in general.

Noted earlier was the fact that current recommendations from the Review of Public Administration explicitly rule out one option for sharpening the current performance management system - namely, competition. The RPA consultation document states that *'…the development of new structures will embrace the principle that the commissioning and delivery of services need not be separated organisationally.'* It then goes on to note that *'These principles point clearly to the development of structures characterised, not by the need to generate competition, but by the creation of partnerships between commissioning and delivery…'* (Para 5.10 *The Review of Public Administration Further Consultation*, March 2005)

The RPA's recommendations for reconfiguring health and social care organisations - in particular, the creation of around five Health and Personal Social Services agencies - in effect reinvent a pre-1990 English NHS model in which health authorities received weighted capitation allocations, planned services and directly managed (and set budgets for) the hospital providers in their area. However, despite acknowledging that there *'must be clear lines of accountability to the Department and the Minister for expenditure, quality and performance*' (Para 5.24 vii), and while noting that performance management remains the remit of the Department, it is not clear in this model how performance improvements are actually to be achieved. In particular, it remains to be seen how providers are to be held to account for their performance. While 'partnership and integration' can generate good things for patients and users, there is a distinct danger that the performance model implied by the RPA's structural reform could fail to provide the necessary incentives and sanctions - or 'bite' - to encourage providers of services to continually seek out new ways to improve their performance.

Overall, from the point of view of performance management, it is hard to see any difference between the RPA's recommendations and the way the current system operates.

Nevertheless, if the RPA's reconfiguration recommendations go ahead, *and* it is accepted that a more robust performance management system, with, for example, more explicit rewards and sanctions, needs to be developed, then serious and urgent thought needs to be given to methods for holding providers to account within these new, more integrated structures.

Overall, however, this Review would suggest that some form of separation between the providers of services and the funders/commissioners of services would be an important factor in sharpening up incentives in the system. Given the particular circumstances in Northern Ireland, its population size and distribution, the political governance structures etc, there needs to be further investigation of the most appropriate form of separation, however. While the four health boards have, in theory, acted as commissioner/purchasers, it is not clear that the full benefits of this arrangement have been achieved. It may be that a single pan-Northern Ireland commissioner would be more appropriate. This arrangement would not preclude some devolution of commissioning to GPs (see below). A crucial aspect of such arrangements however is the design of the rules of engagement and the framework in which commissioners are required to operate. In particular, commissioners would need clear objectives/targets in order to drive performance through their commissioning decisions. The regional level performance management system therefore needs to be reformed to take on serious, long term target setting

In turn, providers themselves need to consider how to devolve functions within their organisations, in particular, ways in which to engage frontline staff with the incentives faced by the organisation as a whole - through, for example, devolution of budgets and associated responsibilities.

The nature and strength of the rewards and sanctions need careful thought. For example, mainly for reasons of scale (and efficiency), the competitive economic environment currently being developed in England is unlikely to be appropriate in Northern Ireland. However, this does not rule out the creative tensions that a separation of purchasing and providing can bring, and nor, for example, the introduction of an activity-based prospective reimbursement system for providers (similar to Payment by Results) with tariff setting (not necessarily fixed at average costs) used to drive improvements in efficiency and selective increases in activity to meet pan-service goals. Nor does it rule out the promotion of greater public and patient awareness of variations in performance in the system.

Moreover, it does not rule out careful expansion of patient choice. While in England choice is being rolled out mainly with a policy emphasis on the leverage it may have over providers (crudely, losing business will stimulate cost and quality improvements), from the patient’s point of view, a more formalised and embedded process of choice (not just of hospital, but over the myriad of decisions that are taken throughout the system which affect a patient’s care) can improve patient satisfaction and service responsiveness. This may be a weaker incentive than that being introduced in England, but the limits to what could realistically offered by way of choice need to be recognised in what is a relatively small system. Nevertheless, there may be certain services, specialties, operations etc where options do exist for real patient choice and where patients would like to exercise greater choice.

In addition to the separation of the tasks of provision and commissioning, ways of both strengthening the involvement of general practitioners in the system and as part of a devolution strategy for commissioning secondary care services, thought should be given to the practical involvement of GPs in the purchasing of care. Again, Northern Ireland has an opportunity to develop its own approach to this form of devolved commissioning which could build on the Local Health and Social Care Groups.

Finally, no system relies on just one or two performance levers. In England, for example, the new payment system and (managed) patient choice are going to run alongside continued use of targets (renamed ‘standards’) and, importantly, an evolving regulatory system at arms length from government which aims to promote the ultimate goals of the system - better quality of care, more efficient and cost effective use of resources. NICE, the National Patients Safety Agency, the Healthcare Commission etc, are important organisations which aim to promote better care. Much of these organisations’ work and output are public goods available for any system to use and from which Northern Ireland could benefit and could inform development of the new HPSS Regulation and Improvement Authority.

Recommendation 23: There is a need to develop an explicit performance management system with rewards and sanctions which provide enough 'bite' to encourage change and innovation in the health and social care system. There are many options for the types of incentives that could be introduced and their design for Northern Ireland. There should however be a commitment to such reform coupled with further investigation of how incentives can be strengthened.

Recommendation 24: Separation of the tasks of service provision and commissioning is an important factor in sharpening incentives. However, the most appropriate structures (eg single pan-Northern Ireland commissioner; devolved GP commissioning etc) needs further investigation.

Recommendation 25: Alongside changes in the performance management system, there is a need to explore the development of a more transparent priority setting process at national level, together with an explicit 'NHS Plan for Northern Ireland' which sets out outcome-based targets linked to new spending paths.

Annexes

Annex A

TERMS OF REFERENCE

Background

A1. Health and social services are essential to the health and social well-being of the people of Northern Ireland and it is important that they are resourced appropriately and that they are delivered efficiently and effectively. Inevitably, they are a major call on the resources available for public spending in Northern Ireland and, as such, it is important that the money allocated is used economically and that it properly reflects the levels of need.

A2. The need for health and social care resources is determined by the complex interplay of a number of factors including age, deprivation, spatial distribution of the population, the consequent economies of scale achieved in health and social care facilities, and ability to contribute towards health and social care costs. Northern Ireland has historically had higher levels of per capita public expenditure on health and social care than England (although less than Scotland and similar to Wales). However, there are contributing factors in terms of high levels of morbidity and mortality from major diseases, such as heart disease, a number of different forms of cancer, and respiratory illness. There are also higher levels of disability, social disadvantage, deprivation and structural issues such as rurality.

A3. The Government has sought to address these needs through continued priority for health and social services in public expenditure. In October 2004, the Northern Ireland Finance Minister, Ian Pearson, announced a substantial increase in health and social services spending when he published the 2005-2008 Draft Priorities and Budget. Between 2004-05 and 2007-08 the resources allocated to the Department of Health, Social Services and Public Safety are planned to increase by 25.1% (this compares with a 32.1% uplift in England over the same period).

A4. However, it is clear that the demand for services continues to rise and there are significant cost pressures facing the health and social services in the coming years. These pose considerable difficulty in relation to funding and the current levels of growth in funding cannot readily be sustained. It is also the case that there are a number of deep-seated problems in the provision of services, with lengthy waiting lists, trolley waits and difficulties in meeting the demand for care and treatment. There is therefore a need to examine both the resources available to health and social services and how these resources are actually utilised. Significant reform in service delivery (particularly in the acute sector) in England has resulted in improved performance and the study should assess how to apply these lessons to Northern Ireland.

A5. In April 2002, HM Treasury published an independent review (by Derek Wanless) of the long term resource requirements for the UK Health Service '*Securing Our Future Health: Taking A Long-Term View*'. Subsequently the National Assembly for Wales also commissioned a review (with Wanless acting as adviser) to examine how the resources for health and social care in Wales could be reformed and services improved.

A6. Professor John Appleby, Chief Economist on Health Policy at the Kings Fund has been invited by the Finance Minister, Ian Pearson, to conduct an independent review of health and social care provision in Northern Ireland. The review will consider the implications of the Wanless studies and the developments in policy in hospital services, primary care and community care in Northern Ireland. The work carried out previously by Wanless will form an integral basis for the review. It will focus on helping to ensure that resources allocated to health and social care are being translated into improved and more cost effective service delivery.

Project Brief

A7. The overall aim of the review is to look at the resourcing of health and social services and to consider how reforms leading to targeted and sustainable investment, effective and efficient delivery structures and appropriate incentive systems can result in improved service delivery. The specific objectives of the review are based on those previously undertaken in Wales and at the UK-wide level. The review will need to consider and make recommendations in the following areas:

- the current position in levels of demand in relation to the levels of funding available;
- the demands of the population for health and social services in NI, taking account of its distinctive characteristics, in terms of long term and sustainable resourcing;
- technological, demographic, medical and other trends over the next two decades that may have implications for the future resource needs of the HPSS sector in NI consistent, where possible, with the approach adopted in the Wanless Review;
- the extent to which resources are being used effectively and efficiently and, if there is evidence of sub-optimal resource utilisation, the issues which are impairing the most efficient and effective use of resources;
- the scope for a more effective use of resources (human, revenue and capital) to bring about a significant improvement in access to, and quality of, services in the HPSS and specifically the optimum balance between prevention, community-based care and acute hospital care;
- ways in which the interactions between the health and social care systems can be improved to maximise performance and the use of resources
- the effectiveness of the organisational and incentive structures, decision-making and accountability processes in health and social care in NI;
- further measures to improve health and well-being which can reduce the demand for health and social services;

Methodology

A8. The review will need to consider the present distribution of resources and the outcomes achieved for the level of spend. It will also be instructive to consider service delivery in terms of comparison with leading practice in England. Performance measures and indicators will also be an important part of the issues to be taken into consideration, and the establishment of incentives to encourage best practice. The review will take evidence from key stakeholders, including those with experience of delivering cutting edge reform in England, with a focus on gathering evidence of best practice and what works.

A9. The review will take written and oral evidence from the key stakeholders in health and social care provision in Northern Ireland and England including:

- Representatives of patients, clients, carers and service users
- The HPSS family of organisations
- Staff, professionals and unions
- Relevant independent and private sector organisations
- Local political representatives
- Community and voluntary Sector
- ‘Change implementers’ in England’s NHS

A10. This review will not revisit areas where reviews have already been conducted or a policy decision has already been made. The review will, however, seek to utilise the broad consultations and analyses which have been undertaken in support of this work. In particular, the review will build on recent work undertaken to develop a twenty year strategy for health and well-being.

A11. Professor Appleby will be supported in conducting the review by a small team of officials drawn from the DHSSPS, DFP and EPU. In addition, advice and guidance will be sought from a formal reference group including local stakeholders and individuals with direct operational experience of the HPSS sector in GB. An informal advisory group of respected academics in the field of health economics will also advise on the direction and outputs of the review.

Output

A12. The product of the review will be a report to the Finance Minister advising on the optimal use of financial resources to deliver and sustain whole system health and social care services for the people of NI over the next 10 years. The report will also highlight the performance indicators and information requirements needed for successfully monitoring delivery of health and social care services.

A13. It is intended that the review will report in late spring 2005 in time to inform the production of the Draft NI Budget.

Review Steering Group

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Review team

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In addition, the team were able to call on help from other staff in the Department of Health, Social Services and Personal Safety and the Department of Finance and Personnel.

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Annex B

Respondents to consultation

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Brian Patterson	British Medical Association
Helen Ferguson	Carers N Ireland
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Brian Dornan	Causeway Health & Social Services Trust
Margaret Gordon	Causeway Health & Social Services Trust
Neil Guckin	Causeway Health & Social Services Trust
Dr Windsor Murdock	Causeway Health & Social Services Trust
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Eileen Thompson	Cedar Foundation
Pip Jaffa	Childcare N Ireland
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Tonya McCormack	Childcare N Ireland
Elaine McElduff	Childcare N Ireland
Christine Best	Crossroads Caring for Carers
Jillian Anderson	DHSSPS
Professor David Bamford	DHSSPS
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Dorothy Jeffrey	DHSSPS
Jim Livingstone	DHSSPS
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Denis McMahon	DHSSPS
Heather Robinson	DHSSPS
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Pam Garside	Eastern Health & Social Services Board
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Dr Tom Black	General Practitioner

Dr Ian Buchanan	General Practitioner
Dr Ian Clements	General Practitioner
Dr Robin Crawford	General Practitioner
Dr Hubert Curran	General Practitioner
Dr Harold Jefferson	General Practitioner
Dr David Ross	General Practitioner
Joleen Connelly	Help the Aged
Duane Farrell	Help the Aged
Pamela McCreedy	KPMG
Norma Evans	Homefirst Community Trust
Alan Gilbert	NHS Confederation
Katherine McDonald	NHS Confederation
Terry Woodhouse	NI Audit Office
Pat McCartan	NI Confederation for Health and Social Services
Bernard Mitchell	NI Confederation for Health and Social Services
Michael Wood	NI Confederation for Health and Social Services
Pauline Stanley	NI Confederation for Health and Social Services
Dr George O’Neill	North & West Health & Social Care Group
Pat Cullen	North & West Health & Social Care Group
Ian Deboys	North & West Health & Social Care Group
Noel Graham	North & West Health & Social Care Group
Linda Wilson	Office of the First Minister and Deputy First Minister
Barney McNeany	Office of the N Ireland Commissioner for Children and Young People
Nigel Williams	Office of the N Ireland Commissioner for Children and Young People
David Finnegan	Review of Public Administration
Gordon Kennedy	Royal College of General Practitioners (NI)
Martin Bradley	Royal College of Nursing (NI)
John Knape	Royal College of Nursing (NI)
William McKee	Royal Group of Hospitals & Dental Hospital Trust
Jillian Anderson	Service Improvement Unit, DHSSPS
Breandan MacCionnaith	Sinn Fein
Stiofan Long	Sinn Fein
John O’Dowd	Sinn Fein
Carmel Hanna	Social, Democratic and Labour Party
Colm Donaghy	Southern Health & Social Services Board
Mairead McAlinden	Southern Health & Social Services Board
Sean McKeever	Southern Health & Social Services Board
Dr Anne Marie Telford	Southern Health & Social Services Board
Stella Cunningham	Southern Health & Social Services Board
Eleanor Hayes	Ulster Community & Hospitals HSS Trust
Alan McFarland	Ulster Unionist Party
Thomas McHaffy	UNISON
Patricia McKeown	UNISON
Dr John Jenkins	United Hospitals HSS Trust
Dominic Burke	Western Health & Social Services Board
Steven Lindsay	Western Health & Social Services Board
Peter McLaughlin	Western Health & Social Services Board
Maggie Reilly	Western Health & Social Services Council

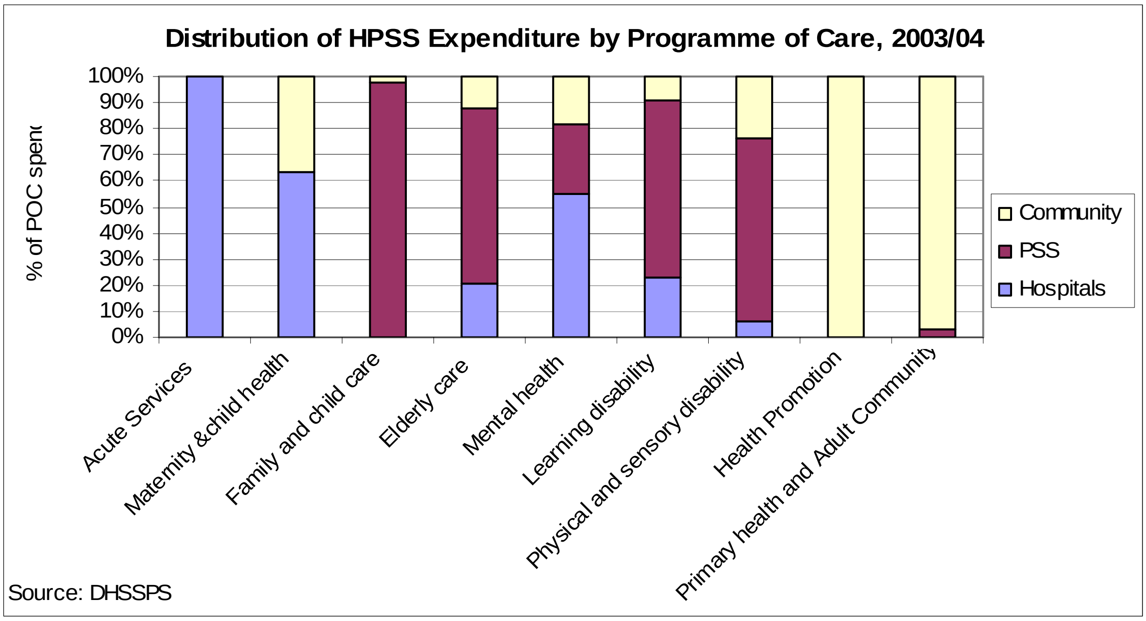
Annex C

TRACKING SPENDING

Hospital, social and community services

C1. In 2003/04 Hospitals accounted for 54% of Trust spend reflecting the importance of the Acute Programme of Care followed by Personal Social Services (33%) and Community Services (12%). However, Figure C.1 shows that for four POC's (Family and Child Care, Elderly Care, Physical & Learning Disability) the greatest amount of expenditure was in Personal Social Services whilst almost all expenditure for Health Promotion and Primary Health was through Community Services. Over the period 1999/00-2003/04 growth in Hospital expenditure was less than both PSS and Community Services. The greatest contribution to the increase in Trust spend over this period was from Hospital Acute Services (41% of total growth) followed by Social Services for the Elderly (17%) reflecting their overall importance in total spend.

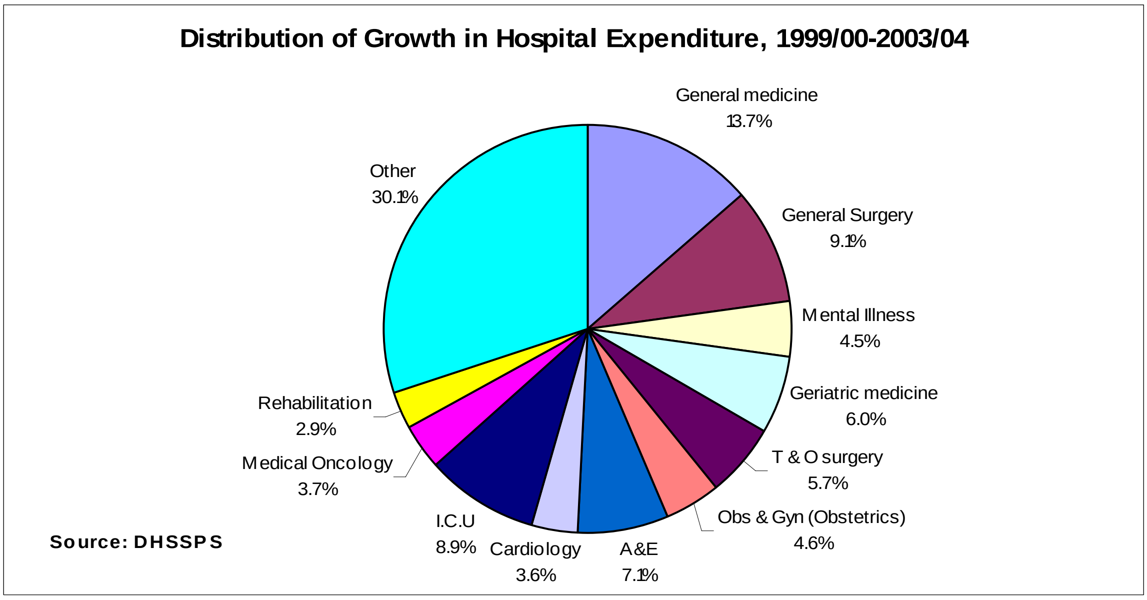
Figure C.1: Whilst hospitals account for most of the HPSS expenditure, they make a relatively minor contribution in terms of most Programmes of Care 2003/04.



Source: DHSSPS

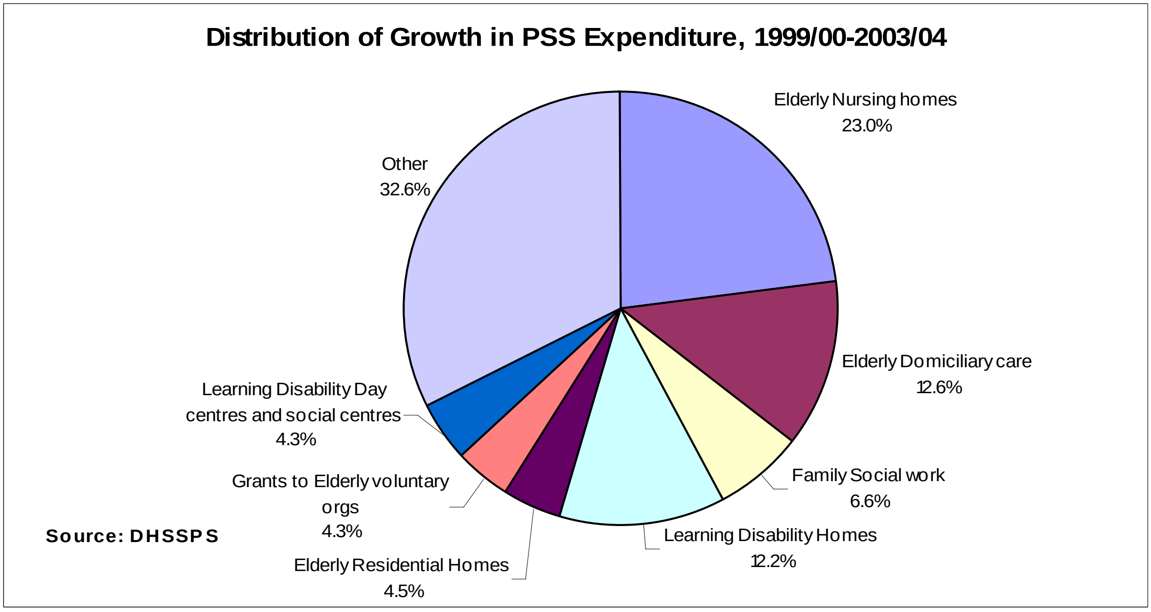
C2. Figure C.2 shows that the largest contributions to the increases in hospital spending during 1999/00-2003/04 came from general medicine and general surgery. Whilst mental illness and geriatric medicine also made a significant contribution to the overall growth, both these specialties experienced lower rates of growth in spend than the hospital average. In comparison, expenditure on A&E and intensive care units grew at a significantly faster rate than the hospital average.

Figure C.2: Contribution to Growth in Hospital Expenditure (+£316m) by Specialty, 1999/00-2003/04



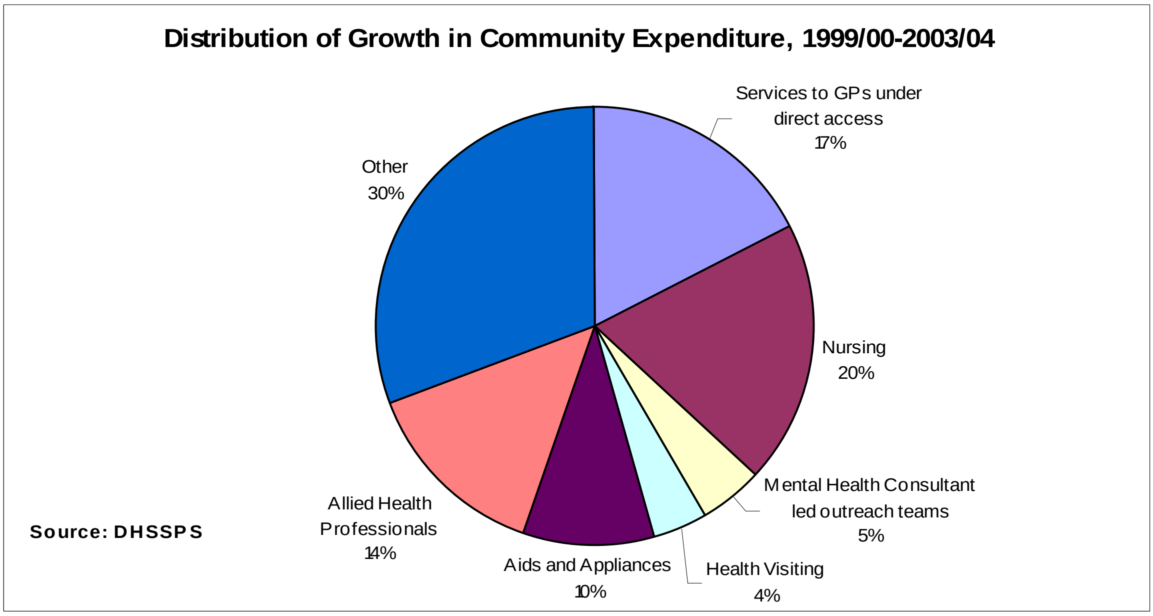
C3. Figure C.3 shows that the largest contribution to the growth in personal social services expenditure over 1999/00-2003/04 came from care for the elderly either in nursing/residential homes or in their own residence. Over this period elderly care expenditure increased on nursing homes (+56%) at a faster rate than residential homes (+16%) and own home (+45%). Indeed, the increase in spend on nursing homes (+£51.7m) was greater than that for general medicine (+£43.2m).

Figure C.3: Contribution to Growth in Personal Social Services Expenditure (+£225m) by Category, 1999/00-2003/04



C4. The growth in expenditure for community services is more widely distributed with only five categories individually accounting for more than 4 per cent of the total increase in spend. Figure C.4 shows that around a fifth of the increase in expenditure on community services went to payments to GP's with direct access payments increasing by 177% over the period compared to 60% growth for all community services.

Figure C.4: Contribution to growth in community services expenditure (+£92m) by category, 1999/00-2003/04



Source: DHSSPS

Annex: D

FURTHER DETAILS OF ASSUMPTIONS USED IN CALCULATING FUTURE RESOURCE REQUIREMENTS OF NI HEALTH & SOCIAL CARE SECTOR

D1. A number of options were considered in estimating the long-term sustainable resource requirements of the Health & Social care sector in Northern Ireland. At the extreme, the Wanless analysis could have been rejected completely and an entirely new model of future resource requirement been developed for Northern Ireland specifically. However, given the resource and time constraints on the Review this would not have been practical. It had been hoped to take the Wanless model which had been based on English data only and populate with Northern Ireland equivalents. Under advice from HM Treasury this approach was also rejected as the model was no longer fit for such a purpose.

D2. Therefore, it was decided that the approach would be to take the Wanless spend projections for the UK and estimate Northern Ireland's need adjusted share. One of the questions for consultation set out in the Interim Report of the Wanless Review related to whether health trends would effect different parts of the UK in different ways. In general, the consultation responses indicated that the impact of health trends would be similar throughout the UK but that there would be some differences related to population characteristics. In particular there were differences in population growth, age structure and morbidity. In terms of technology and workforce issues however, international trends were expected to dominate.

D3. The Wanless projections of health spend are presented in terms of both public spending and total health spending as a share of GDP i.e. including the private sector[121]. It could be argued that total health spending should be the focus of attention and that the public sector in Northern Ireland should receive additional funds for the relatively under-developed level of private provision. However, as shown in Section 3.3.2 it is not clear how far Northern Ireland is behind the rest of the UK in this respect, whilst the consultation process indicated that the private sector was growing in Northern Ireland.

D4. The first stage of the analysis was to calculate the baseline figure for England in 2002/03. Although Wanless produced figures for the UK as a whole, the subsequent 2002 Budget set out the comparable figures for England[122]. A further complicating factor is that subsequent Budgets in both Northern Ireland and the UK as a whole for the period up to 2007/08 have diverged from the expenditure projections sets out by Wanless. This could have been taken

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[121] Private health spending is assumed in the Wanless Review to remain at 1.2 per cent of GDP throughout the forecast period although in figures presented as part of the 2004 Spending Review HM-Treasury increased the share to 1.4 per cent.

[122] The UK baseline figure was not used as this would have required the needs adjusted shares for Scotland and Wales to also have been calculated. In addition, the HM Treasury figures for England were used in preference of taking a simple population share to reflect that health spend per head is currently lower in England than in the rest of the UK. The HM treasury figures show however, that England's share of total UK spending was projected to increase by 0.1pp a year over period 2002/03 to 2007/08.

account of through, for example, assuming that growth would change in the subsequent periods to compensate, with the result that overall growth up to 2022/23 would have remained the same. However, given that the long-term perspective is being considered it was decided not to consider any short-term variations from the Wanless projections.

D5. The treatment of Personal Social Services was more complicated as the Wanless projections covered only 60% of total PSS expenditure. In addition, the projections presented in the Final Report represent core resource requirements on the basis of the present position adjusted for population and changes in the level of ill health. As a consequence, it is acknowledged that the projections under-estimate the additional resources required. In particular, they do not take into account the resources required to deliver a higher quality service. Whilst the growth rates for heath expenditure may be higher than that which would be expected for more fully developed social services spend projections it was considered reasonable to assume that the growth rate for social services expenditure would be the same as that for health services.

Annex: E

CRITIQUE OF NI REVISIONS TO NAS MODEL

In order to inform the Reviews examination of allocation models in the context of providing a guide to future spending on health and social care in Northern Ireland, an initial critique of the revisions to the NAS model was commissioned from Dr Nigel Rice, at the Centre for Health Economics, University of York.

The following report is based on material supplied by DHSPSS, including background statistical work in support of the revisions suggested.

SUMMARY

E1. The Northern Ireland Executive's Needs and Effectiveness Evaluation (NEE) study is an attempt to evaluate the assumptions underlying the Treasury Needs Assessment Study (NAS) model and to compare these to perceived current knowledge and evidence of the need for health care in Northern Ireland (NI). This exercise resulted in a set of suggested revisions to the NAS model that benefits NI compared to England.

E2. The Needs Assessment Study carried out by the Treasury in 1979 looked at how the need for health care in Scotland, Wales and Northern Ireland compared to England. This exercise resulted in a model (the NAS model) that has been used to inform thinking about the distribution of resources but has not thus far been used to set actual allocations. Since 1979 the NAS model has been updated, the last complete update related to November 1994.

E3. Currently, allocations to NI are based on historical allocation decisions augmented by the Barnett formula. The Barnett formula is a mechanism used to allocate new monies to the devolved administrations based on population shares. It is not weighted for need.

E4. Should the use of the Barnett formula be challenged as an appropriate mechanism to allocate monies then the NAS model would be a needs-based approach readily available to the Treasury. On the basis of the results from the 1994 update of NAS, Health and Personal Social Services (HPSS) in Northern Ireland was estimated to be *over-funded* by £74 million.

E5. The NEE contains two fundamental pieces of analysis. The first is a routine update of the NAS model. This simply updates the population, morbidity and deprivation data together with updates to the weights attached to these (based on evidence from English resource allocation). The assumptions behind the updates appear sensible. Updating the NAS model suggests that HPSS is *over-funded,* relative to its current funding position (based on the Barnett formula), by around £35million.

E6. The second analysis suggests fairly substantial revisions to the NAS model made on the basis of judgement informed by research evidence. A key component to the revisions is the change in emphasis away from morbidity and towards deprivation as exerting influence on the need for health care and the percentage of total expenditures that should be weighted by these needs factors. A further important element is the suggested increased weighting afforded to sparsity which is intended to reflect the greater costs associated with providing services to rural and remote areas.

E7. Revisions to the model are more ambitious and result in HPSS being *underfunded* by an estimated £135 million relative to its current funding position.

E8. More speculative adjustments are also noted which if implemented would raise the estimated *underfunding* to as much as £233 million. However, it is stressed that further probing of these issues is required before these additional adjustments are recommended.

E9. The main difficulty is that the revisions offered to the NAS Treasury model are based largely on informed judgement and interpretations of research evidence. This is particularly the case for arguments made to shift the emphasis from morbidity towards deprivation factors. I am not of the opinion that the arguments presented are sufficiently well advanced to suggest these fundamental revisions to the model represent a serious candidate for an alternative needs based approach.

E10. At best, the arguments made would form the basis of initiating a dialogue with the Treasury about the most appropriate needs-based mechanism for allocating resources. This is not to say that the claims are without foundation but further evidence, backed by empirical analysis, would need to be presented to support the revisions offered before they can be taken seriously.

E11. Other fundamental revisions to the NAS model are supported by research evidence of a more robust nature and, there does appear to be prima facie evidence of a case for claiming the costs of providing health and social care services in remote and rural areas in NI is more expensive than England. However, I feel that further research is required to support these assertions.

E12. In its present form, it is difficult to see how the judgements underlying the revisions could be used to gain a consensus among interested parties that these offer a more appropriate means of assessing relative needs. In my view, should a needs based approach be adopted then an analysis of need supported by empirical evidence obtained through a statistical analysis of relative health care needs across the countries of the UK is required. However, it is recognised that such a study would be data intensive requiring information measured at a meaningful level of aggregation and of a comparable nature across each of the devolved administrations.

E13. While the evidence on NI comparative levels of morbidity and deprivation suggests a needs weighted approach as an appropriate mechanism to ensure an equitable allocation of resources, the evidence presented is not, in my opinion, of sufficient scientific quality and objectivity to suggest the revised model as a credible alternative to the NAS model. Ultimately both the NAS and the revised model are based on informed opinion and judgement and arguments concerning the plausibility of the NAS model could just as easily be aimed at the revised model offered by the NEE exercise.

E14. In short, whilst the NAS model may itself be imperfect, it has the support of the Treasury as a needs based approach for potentially informing relative health care allocations across the devolved administrations. Convincing the Treasury that the revisions offered by the NEE exercise are a credible alternative to NAS would, in my opinion, prove difficult.

E15. In the absence of a thorough statistical analysis of the relationship between need and health care use across the devolved administrations, I would suggest that the *routine update* to the NAS model provides the most appropriate currently available method for NI to assess its potential funding position under needs weighting.

MAIN REPORT

Introduction

E16. An interdepartmental study on the relative public expenditure needs of England, Scotland, Wales and Northern Ireland was carried out by HM Treasury in 1979. The exercise, known as the Needs Assessment Study, resulted in a model, the NAS Model, which looked at how need for health care in each of the devolved administrations compared to England. It was not intended to measure absolute need. Since 1979 the NAS model has been updated, the last complete update related to November 1994. The model has been used to inform thinking about the distribution of resources but has not thus far been used to set actual allocations. The 1994 update of NAS indicated that, on the basis of the model assumptions, Health and Personal Social Services (HPSS) in Northern Ireland was over-funded by £74 million.

E17. The current system of allocations to Northern Ireland (NI) is based on historical allocation decisions augmented by the Barnett formula. During the 1960s and 1970s, public expenditure plans for Scotland, Wales and NI were settled collectively and by negotiation within the wider public expenditure framework.[123] This set the precedent for funding to the devolved administrations and forms the core of the budgets allocated. It has been claimed that this core reflects the higher needs, which it is argued the devolved administrations have, because it was, at least in part, determined by arguments over need relative to England[2].

E18. The Barnett formula is a mechanism used to allocate new monies for comparable (to England) programmes to the devolved administrations based on their population shares. It only applies to changes on spending plans and the underlying core remains unaffected.

E19. A criticism of a strict application of the Barnett formula is that it will result in convergence in per capita spending as the core is diluted by new monies which

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[123] See Edwards, T. (2001) The Barnett Formula. *House of Commons Library, Research Paper 01/108*.

is allocated on a population basis alone. Presently there appears to be little evidence that convergence is taking place.[124]

E20. Should the use of the Barnett formula be challenged as an appropriate mechanism to allocate monies then the NAS model would be a needs-based approach readily available to the Treasury. The NI Executive's Needs and Effectiveness Evaluation (NEE) study is an attempt to evaluate the assumptions underlying the NAS model and compare these to perceived current knowledge and evidence of the need for health care in NI.

E21. The NEE contains two fundamental pieces of analysis. The first is a routine update of the NAS model. This simply updates the population, morbidity and deprivation data together with updates to the weights attached to these (for example by updating the cost-weights attached to population demographic data). The second analysis suggests fairly substantial revisions to the NAS model made on the basis of judgement informed by research evidence. A key component to the revisions is the change in emphasis away from morbidity and towards deprivation as exerting influence on the need for health care and the percentage of total expenditures that should be weighted by these needs factors. A second important element is the suggested increased weighting afforded to sparsity which is intended to reflect the greater costs associated with providing services to rural and remote areas.

E22. The simple update of the 1994 NAS model results in an estimated *over-funding* of HPSS of around £35m (needs index of 108 for NI compared to England index of 100). Revisions to the model are more ambitious and result in NI being *underfunded* by £134m (the needs index increases to 117). These revisions are based on what is termed "clear and objective evidence".

E23. More speculative adjustments are also noted which if implemented would raise the *underfunding* to as much as £233m. These adjustments are based on what is termed "professional judgement supported by research". However, it is stressed that further probing of these issues is required before these additional adjustments are recommended.[125]

E24. The purpose of this note is to assess the validity and robustness of the suggested revisions to the NAS model.

The NAS model

E25. The NAS model calculates NI expected need for health care compared to England on the basis of population size and structure, their health and social care needs and cost factors due, for example, to rurality. Each of the needs and population factors are expressed as a ratio to their equivalent English factor. For example, since SMRs are greater in NI compared to England this needs factor would attain a ratio greater than 1.

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[124] See Midwinter, A. (2002) *Northern Ireland's Expenditure Needs: A Preliminary Assessment.* Research Paper 81/02; Research and Library services, Northern Ireland Assembly.

[125] P A21.33: Appendix 2.5. Review of Needs Assessment Study (NAS) Model – Hospital and Community Health Services (HCHS), Family Health Services (FHS), Personal Social Services (PSS), and Capital.

E26. Individual factors may be given a weight between 0 and 1 to indicate its assumed influence on the need for health care. For example, SMR < 75 is weighted by 0.6 as a morbidity indicator for Health and Community Health Services (HCHS); composite deprivation indices are derived by weighting individual deprivation variables and summing across these.

E27. The individual indicators are then multiplied by the proportion of expenditure to which it is assumed to relate. For example, for HCHS morbidity factors are applied to 77% of expenditure, whereas population demographic factors are applied to 100% of expenditure. Accordingly morbidity is afforded less relative weight in determining putative allocations than demographics. These are then multiplied by each other to produce a composite needs, population and cost (rurality) factor. It is this composite factor that could form the basis of future allocations.

E28. Details of the NAS model for each of the programme components, HCHS, Family Health Services (FHS) and Personal Social Services (PSS) are provided in Appendix I.

E29. The NAS model methodology is *normative* and *judgemental*. It is assumed that the indicators chosen to reflect need have a causal relationship with expenditure or service use. These indicators were selected on the basis of plausibility and judgement and were not chosen or indeed weighted on the basis of a statistical analysis of the relationship between need and the use of health care. In this respect the NAS methodology departs from modern resource allocation models employed to distribute monies across trusts, regions and health boards within England, Wales, Scotland and NI.

Routine update to 1994 NAS Model

E30. The routine update to the 1994 NAS model consists of applying current or more recent data than those used previously. Accordingly, the population data and data on morbidity and deprivation indicators are updated. Also, the weights applied to the population demographics are updated to reflect recent evidence from HCHS work in England. The key routine updates are outlined below.

E31. The rationale for updating the population data from 1994 to 2001 (and maintaining updated data) is NI's faster growing population and changing age profile, such that (taken from Chapter 2[4]):

- By 2010 the population aged 65+ is expected to grow by 15%: the corresponding figures for England, Scotland and Wales are 8%, 7% and 7% respectively.
- Growth rates for the 85+ years age group are expected to show even greater differences between NI and the rest of GB (to 2025).[126]
- However, it ought to be noted that by 2025, older people will still make up a smaller proportion of the population in NI compared to the proportion of population in the rest of GB.

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[126] Chapter 2 – Assessing the needs of the population.

- NI has a young population with 30% aged under 20 years compared to 25% in England. It also has a higher birth rate (11% higher), although this gap is narrowing.

E32. The population demographic structure has implications for needs assessment as the very young and elderly have higher than average health care expenditures. Based on expenditures per head in 1997/98 on HCHS, it is claimed that it would take a 1% increase in resources per year in real terms to meet the additional costs associated with demographic growth and change up to 2015 and at least as much thereafter.[127] Note that Midwinter points to similar calculations for Scotland resulting in an increase of only 0.23% over three years.[128]

E33. The second adjustment relates to the weights applied to the age profiles (paragraphs (iii) and (iv), pA2.82 of Appendix 2.5.). These are updated to reflect the weight used for HCHS resource allocation in England (using 1997-99 data). It is claimed that updating the cost-weights would lead to a reduction in the 1994 NAS calculated over-funding of NI.

E34. It is further claimed that UK wide weights should be applied (as opposed to weights from England only). This would increase allocations to NI (paragraph (iv)) due, it appears, to NI and Scotland having greater per head expenditures for the 45+ age groups compared to England (although weights for younger age groups would decrease).[129] However it is not clear what proposals are made to calculate UK weights. If these were calculated on the basis of a population-weighted average of England, Scotland, Wales and Northern Ireland then they would be heavily influenced by English cost weights due to the superior population and the benefit to NI of using UK weights may not be as great as assumed. However, in principle it appears sensible to base weights on a UK average rather than a single country alone.

E35. The simple update of data and age cost-weights is of little contention and appears to be a suitable way to proceed to gauge NI comparative level of need within the context of the NAS approach.

Model revisions

E36. Model revisions are based on the above routine updates to the 1994 NAS model together with various changes to the individual indicators within each of the expenditures programmes, changes to the relative weight that morbidity and deprivation factors are afforded and revisions to the amount of expenditure to which need is applied.

E37. The main features of the recommended revisions are outlined below.

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[127] Appendix 2.2. Study 2 – Needs and Effectiveness Evaluation: Relationship between Age and Cost of Service. Section: Summary of Detailed Analysis: Hospital, Community and Health Services.

[128] P20, para. 63. Midwinter, A. (2002) *Northern Ireland's Expenditure Needs: A Preliminary Assessment.* Research Paper 81/02; Research and Library services, Northern Ireland Assembly.

[129] See Annex 1, Table 1: Expenditures (£) per head of population by age (HCHS excluding maternity services), Appendix 2: Detailed Papers on Factors Affecting Need.

Need in relation to morbidity and deprivation

E38. The major revisions with respect to need are:

- an adjustment to the proportion of expenditure to which needs factors are applied such that this becomes 100% for HCHS, FHS and all 3 PSS components. Currently the NAS model applies needs factors to 90.5% of expenditure for HCHS, 76% for FHS, 52% for PSS Elderly, 62% PSS Children and 32% PSS Other,
- a shift in emphasis within programmes such that expenditure factors for morbidity and deprivation are afforded equal weight. For example, for HCHS morbidity is given an expenditure weight of 77% and deprivation a weight of 13.5%. A shift to equal weight together with needs factors being applied to 100% of expenditure would necessarily imply weights of 50% and 50% respectively.

E39. Shifting the emphasis from morbidity factors towards deprivation and increasing the amount of expenditure to which needs factors are to be applied benefits NI due to it having higher levels of deprivation compared to England. For example, the following comparisons are noted:

- SMR < 75 – NI Standardised Mortality Ratio for those aged under 75 is 4% above the UK average (England is 3% below UK average).
- NI has the lowest proportion of the working age population in employment – 66% compared to 76% in England. Rates for the very long term unemployed (5 years or more) is higher in NI (18.3%) compared to England (highest figure across English regions is 11.7% in the North East).
- Income Support Benefit – The level of recipients is 68% higher in NI compared to England.
- Disadvantaged children – The proportion of lone parent households is higher in NI (12.6%) compared to England (9.1%).

E40. The overall effect of the revisions is that per capita spending in NI should be at least 17% higher than that of England. This is equated to an additional £190m for 2000-01.[130]

E41. The recommendations of applying needs factors to 100% of expenditure and shifting the emphasis from morbidity towards deprivation are based on a review of resource allocation models in the UK and how these have been implemented. The arguments are set out in the document “Health and social care needs: The impact of deprivation”.

E42. For example, it is claimed that the mix of deprivation, morbidity, and mortality indicators in the Acute Needs Index for HCHS expenditures in England suggests that their relative influence is in the ratio 40%: 40%: 20%. The `Arbuthnott Index’ used in Scotland comprises of a composite indicator of need consisting of three deprivation indicators and one mortality indicator (all of equal weighting) suggesting a ratio of 75% to 25% in favour of deprivation.

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[130] Paragraph 8, page 5: Needs and Effectiveness Evaluation: Health and Social Care: Executive Summary, July 2002.

E43. The paper rightly states that “direct measures of ill-health or morbidity would be used within the HCHS and FHS components of the NAS model as the link between such indicators and this type of service need is clear and direct.” (p1, paragraph 3.) It also notes that evidence on morbidity is often limited in routinely collected data sources and that the morbidity data collected is often problematic through biases inherent in self-reported measures. This is often the case when using small area statistics (the basis of many resource allocation models) where area socio-economic and deprivation data are by comparison more abundant.

E44. As a consequence, the majority of resource allocation models use, alongside limited morbidity data, mortality, socio-economic and deprivation data. These are often viewed as proxies for morbidity. However, they can also be seen as determinants of the underlying social causes of the need for health care.[131]

E45. Given that morbidity data is often in short supply and that socio-economic and deprivation data is relatively abundant it is not surprising that resource allocation models contain relatively more deprivation indicators compared to morbidity indicators.

E46. The approach often adopted in resource allocation models is to view both morbidity and socio-economic or deprivation variables as drivers of health care need. The relationship between these factors is derived from a regression model of service use on such indicators. Many factors combine to influence the outcome of such a process including the assumptions made in specifying the model, the degree of collinearity between the variables and the order in which variables are added to a model. The weight afforded to morbidity and deprivation is determined by the regression model estimates.

E47. The NAS model appears to view deprivation and morbidity as having distinct influences on the need for health care and on this basis they are provided with weights based on judgement. If it is assumed that deprivation influences the need for health care largely through its impact on morbidity, then a normative analysis would place greater weight on legitimate measures of morbidity. This appears in to be the case with NAS allocations for HCHS expenditures where mortality is applied to 77% and deprivation to 7.5% of expenditure.

E48. The basic problem with the revisions is that they are largely judgemental but based on interpretations of research evidence that employs a different (regression based) approach to assessing relative needs. In the absence of a statistical analysis of relative health care needs across the countries of the UK, it is difficult to see how the judgements underlying the revisions could be used to gain a consensus among interested parties that these offer a more appropriate means of assessing relative needs.

E49. While the evidence on NI comparative levels of morbidity and deprivation suggests a needs weighted approach is required to ensure an equitable allocation of resources, the evidence presented is not, in my opinion, of

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[131] For example, the presence of carers in the home will influence demand for health care, or high earning households may have a greater predisposition to use private health care.

sufficient scientific quality and objectivity to support the revised model as a credible alternative to the NAS model.

E50. Ultimately both models are based on informed opinion and judgement and arguments concerning the plausibility of the NAS model could just as easily be aimed at the revised model offered by the NEE exercise.

E51. At best, the arguments made could form the basis of initiating a dialogue with the Treasury about the most appropriate needs-based mechanism for allocating resources to the devolved administrations. However, I am not of the opinion that the arguments are sufficiently well advanced to suggest the revised model is a serious candidate for an alternative needs based approach.

Sparsity

E52. The NAS model includes a `sparsity factor' to compensate for the additional cost of providing services in sparsely populated areas. The sparsity factor is calculated as follows:

- For HCHS sparsity is based on the proportion of people living in District Council areas with a population density of less than 1 person per hectare compared to the equivalent proportion in England. The factor weight afforded this variable is 12.5%. It is unclear what the rationale was applied to determine this weight.
- For FHS the sparsity is calculated by expressing total GMS expenditure including expenditure on Rural Practice Payments (RPPs) as a percentage of GMS expenditure without RPPs. This is then expressed as a ratio to the equivalent English figure.
- For PSS the same sparsity variable and weight as applied to HCHS is used.

E53. The sparsity factor is then applied to 12.5% of HCHS expenditures, 28% of FHS expenditures and 50% of each of the components of PSS expenditures. These sparsity expenditure weights are intended to reflect the travel-related elements of each of the health and social care components. For example, it is estimated that 12.5% of HCHS expenditure involves travel-related services (ambulance and community health services).

E54. The Executive's NEE study, drawing on research into the additional costs of providing health and social care to sparsely populated areas, suggests that a sparsity cost premium of 20%, rather than the 12.5% assumed for HCHS would by justifiable for NI. A more ambitious estimate of 30% is also suggested. For PSS the same estimate of 30% (again rather than 12.5%) is also suggested.

E55. These estimates are derived from a study by MSA Ferndale[132] that involves estimating the travel related costs that would be incurred if equality of access to services (independent of location) were to be achieved in all areas. The costs are then related, via regression based methods, to relevant characteristics of areas considered. This relationship between cost and area characteristics allows the researchers to impute the travel costs for other areas not included in the original research.

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[132] MSA Ferndale. (2001) The Costliness of Rurality in the Provision of Health and Social Services, Internal Project Paper.

E56. This research provides evidence that the travel cost of providing health and social care to remote areas in NI is more expensive per head than in England. The research contains a couple of fundamental assumptions - for example, that NI Health Boards can be considered operationally equivalent to Districts in England, and that the ratio of travel costs for Home Care Services between NI and England can be applied to all other health and social care services - and it would be useful to assess the materiality of these assumptions. However, there does appear to be prima facie evidence of a case for claiming the costs of providing health and social care services to remote and rural areas in NI is more expensive than England.

More speculative revisions (to be further probed)

E57. These, more speculative, adjustments concern the influence that individual deprivation indicators exert on the overall deprivation index for each of the expenditure programmes. These are summarised in Appendix II.

E58. It is further suggested that NI should be compensated for the additional costs faced by the DHSS due to lower levels of provision of private health care in NI compared to England. The argument appears to be that in England the private sector releases the burden on the publicly provided health service (hence the public sector receives a greater allocation than it needs) and that this is not the case in NI, at least not to the same extent. It is claimed that an appropriate compensation could amount to £25m.

E59. A more detailed analysis of the comparative use of private nursing homes was provided as supporting evidence for the differential cost NI faces per capita compared to England. A survey of self-funding of nursing home places in NI suggests this represents 15% of all nursing homes places. The comparable figure for England is estimated at 33%. Reasons provided for the lower level of self-financing in NI include higher historical levels of unemployment, lower wages and lower property values. The analysis suggests there is prima facie evidence of a higher burden placed on the public sector in NI to provide nursing home care.

E60. A further adjustment is suggested to compensate for the perceived additional costs arising from the tensions in NI resulting in higher levels of stress and an increased burden on the health service. An estimate of £18m is claimed as an appropriate amount. This appears to be based largely on an analysis of anti-depressants and ulcer healing drugs. It is claimed that the higher use of these drugs in NI compared to England is related to the NI “Troubles”. It is unclear why these additional costs are not accounted for through increased levels of morbidity and why a separate adjustment as proposed is required.

E61. It is claimed that should the above factors be accounted for NI would currently be *underfunded* by as much as £233m.

E62. The proposed revisions are largely judgemental and not grounded on strong evidence. It is noted that the report[133] lists these revisions as “Other Issues to be Probed (identified through professional judgement supported by research)”. Further research on these issues is required before firm recommendations for changes to the NAS model should be made.

Conclusions

E63. Currently the system of allocating HPSS funding to NI is based on the Barnett formula. This system allocates monies on the basis of a baseline that forms the core of the budget together with a formulaic element that applies to new monies. The baseline reflects historic allocations to devolved administrations while the formulaic element allocates on the basis of population shares alone. It only applies to changes on spending plans and the underlying baselines remain unaffected. The Barnett formula has been criticised on the grounds that is does not reflect needs, and that over time the formulaic element will ensure convergence in spending across the devolved administrations.

E64. The Treasury 1994 NAS model is suggested as a readily available alternative to the Barnett formula that has the benefit of containing a weight for need. Under needs weighting, it is argued that NI, which has higher levels of morbidity and deprivation, would benefit comparatively to England. However, an application of the 1994 NAS model indicates that NI is currently *over-funded* by £74m. A simple update of the model using currently available data suggests an *over-funding* of £35m. The revisions to the NAS model suggest that NI is *under-funded* by £135m.

E65. The suggested revisions to the NAS Treasury model are based largely on informed judgement and interpretations of research evidence. This is particularly the case for arguments made to shift the emphasis from morbidity towards deprivation factors. I am not of the opinion that the arguments presented are sufficiently well advanced to suggest these fundamental revisions to the model represent a serious candidate for an alternative needs based approach. At best, the arguments made would form the basis of initiating a dialogue with the Treasury about the most appropriate needs-based mechanism for allocating resources. This is not to say that the claims are without foundation but further evidence, backed by empirical analysis, would need to be presented to support the revisions offered before they can be taken seriously.

E66. Other fundamental revisions to the NAS model are supported by research evidence of a more robust nature and there does appear to be prima facie evidence of a case for claiming the costs of providing health and social care services in remote and rural areas in NI is more expensive than England. However, I feel that further research is required to support these assertions.

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[133] P A21.31: Appendix 2.5. Review of Needs Assessment Study (NAS) Model – Hospital and Community Health Services (HCHS), Family Health Services (FHS), Personal Social Services (PSS), and Capital.

E67. Overall, while some elements of the proposed revisions are supported by empirical research providing prima facia evidence for a claim for increased funding support, there is a general lack of rigorous statistical analysis offered from which an independent analyst could assess with any great degree of certainty the validity of the claims made.

E68. In the absence of a thorough statistical analysis of the relationship between need and health care use across the countries of the UK, I would suggest that the updated NAS model provides the most appropriate available method for NI to assess its potential funding position under needs weighting.

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Centre for Health Economics
February 2005

Appendix I

The NAS model employs a similar methodology for HCHS, FHS and PSS components of expenditure but differs in the groupings used to define population demographics, the chosen indicators of need and the costs of delivering services. The key components to the NAS model are:

HCHS –

- Population structure - the population is broken down by births and 7 selected age bands (0-4 through to 85+) and weighted by English HCHS expenditure weights.
- Morbidity - measured using SMR < 75 with a weighting of 0.6.
- Deprivation – based on a composite indicator consisting of 3 equally weighted factors: Isolated Elderly, Housing Conditions, and Income Support.
- Fertility – a measure of the average number of children that women would have over child bearing years assuming age-specific fertility rates.
- Sparsity – Proportion of people living in District Council areas with a population density of less than 1 person per hectare.
- Resource cost differences – based on additional HCHS expenditure experienced in Thames regions of England compared to total English HCHS allocation.
- Teaching Expenses adjustment

The factors are applied to the following percentage of expenditure:
Population structure: 100%
Morbidity: 77%
Deprivation: 7.5%
Fertility: 6%
Sparsity: 12.5%

FHS –

- Population structure – Similar procedure to HCHS but using five age categories (0-4, 5-15, 16-64, 65-74, 75+) and weighted by English FHS expenditure weights.
- Morbidity – combination of SMR < 75 and an indicator of the percentage of population in physically demanding (manual) occupations. The two factors are weighted in ratio 0.8:0.2.
- Deprivation – based on a composite index consisting of the following factors: Isolated Elderly, Housing Conditions, IS recipients, Children in Lone Parent Families on IS, and Children in Lone Parent Families. The relative weightings applied to these are 0.3, 0.1, 0.4, 0.1, and 0.1 respectively.
- Fertility – as HCHS
- Sparsity - calculated by expressing total GMS expenditure including expenditure on Rural Practice Payments (RPPs) as a percentage of GMS expenditure without RPPs.

The factors are applied to the following percentage of expenditure:

Population structure: 100%
Morbidity: 40%
Deprivation: 30%
Fertility: 6%
Sparsity: 28%

PSS –

(1) Elderly (population aged 65+):

- Population structure – divided into 3 sub-groups (65-74, 75-84, 85+) and weighted using weights 1.0, 4.5 and 14.2 respectively.
- Deprivation – Composite index consisting IS recipients, Isolated Elderly and Housing Amenities. The three factors are weighted in ratio 0.3, 0.6, 0.1 respectively.
- Disability – prevalence of disability among adult population.
- Sparsity – as with HCHS
- Resource cost differences – based on comparison of average earnings of PSS professionals.

The factors are applied to the following percentage of expenditure:

Deprivation: 50%
Disability: 2%
Sparsity: 50%

An overall index is calculated by multiplying the following factors: Population; Deprivation, Disability and Sparsity; and Resource cost differences.

(2) Children (< 18):

- Population structure – single weight applied to under 18 age group.
- Deprivation – composite index consisting of IS recipients in under 60 age group, Children in Single Parent Families (2 versions of), Housing Conditions, Population density. These factors are weighted in ratio: 0.2, 0.125, 0.125, 0.05 and 0.5 respectively.
- Disability – as per PSS Elderly.
- Sparsity – as per PSS Elderly
- Resource Cost Difference – as per PSS Elderly.

The factors are applied to the following percentage of expenditure:

Deprivation: 60%
Disability: 2%
Sparsity: 50%

An overall index is calculated by multiplying the following factors: Population; Deprivation, Disability and Sparsity; and Resource cost differences.

(3) Other:

- Population structure – single weight applied to 18 to 64 year age group.
- Deprivation – composite index consisting of IS recipients in under 60 age group, Children in Single Parent Families (2 versions of), Housing Conditions. These factors are weighted in ratio: 0.5, 0.2, 0.2, and 0.1 respectively.
- Disability – as per PSS Elderly.

- Sparsity – as per PSS Elderly
- Resource Cost Difference – as per PSS Elderly.

The factors are applied to the following percentage of expenditure:

Deprivation: 30%
Disability: 2%
Sparsity: 50%

An overall index is calculated by multiplying the following factors: Population; Deprivation, Disability and Sparsity; and Resource cost differences.

An overall need factor for PSS is calculated by averaging the needs factors for the three sub-programmes using weights that are proportions of total PSS spending in England on each group. The weights are 46% for elderly, 34% for children and 20% for other adults.

Appendix II

These, more speculative, adjustments concern the influence that individual indicators exert on the overall deprivation indicators for each of the expenditure programmes.

These are summarised as follows[134]:

HCHS –
- Isolated Elderly – increase weight from 0.33 to 0.40
- Poverty – increase weight from 0.33 to 0.50
- Housing Conditions – reduce weight from 0.33 to 0.10

FHS-
- Isolated Elderly – reduce weight from 0.30 to 0.20
- Poverty – retain at 0.40
- Lone Parent Families – increase weight from 0.10 to 0.15
- Lone Parent Families in Poverty – increase weight from 0.10 to 0.15
- Housing Conditions – retain at 0.10

PSS –

Elderly
- Isolated Elderly –reduce weight from 0.60 to 0.30
- Elderly Poverty – increase weight from 0.30 to 0.60
- Housing Amenities – retain weight at 0.10

Children
- Population Density – reduce weight from 0.50 to 0.30
- Adult Poverty – increase weight from 0.20 to 0.30
- Lone Parent Families – reduce weight from 0.125 to 0.10
- Lone Parent Families in Poverty – increase weight from 0.125 to 0.20
- Housing Conditions – increase weight from 0.05 to 0.10

Other
- All weights remain unchanged

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[134] P A21.31: Appendix 2.5. Review of Needs Assessment Study (NAS) Model – Hospital and Community Health Services (HCHS), Family Health Services (FHS), Personal Social Services (PSS), and Capital.

Annex: F

EQ-5D: Summary measurement of population health

F1. The Health Survey for England (2003) provides EQ-5D data for some 16,000 adults sampled as part of a national survey conducted in the recent past. The EQ-5D data in this survey are unfortunately limited to the reported problem levels on each of the dimensions of EQ-5D since the English survey omitted self-rated health status recorded on a 0-100 visual analogue scale (VAS). These data are available for the Northern Ireland survey however.

F2. To enable comparison of health status at a population level, EQ-5D data were first converted into an index form (EQ-$5D_{index}$). This index is computed by applying *social preference weights* to the self-reported level of problem on each of the five dimensions. These weights were previously established by surveying a representative sample of the UK population using Time Trade-Off (TTO) procedures as part of the Measurement and Valuation of Health (MVH) project commissioned in 1993 for the then Department of Health and Social Security. These TTO-based social preference weights have been widely reported and form part of the reference case methodology advocated for technology appraisals conducted by the National Institute for Clinical Excellence.

F3. Mean EQ-$5D_{index}$ values were computed separately for men and women in the HSE (2003) survey. Values were computed for successive 10-year age groups in each case. Hence for each cell in this 7 by 2 matrix it is possible to identify a mean EQ-$5D_{index}$ and its corresponding standard deviation. This process establishes a set of normative population values for EQ-5D, in effect defining the *expected* value for an individual of a given age and gender.

F4. The *observed* EQ-$5D_{index}$ for each respondent in the Northern Ireland survey was standardised using the normative population values obtained from the HSE(2003) survey using the following transformation

$$\text{EQ-5D}^* = 1.0 - [(\text{EQ-5D}_{obs} - \text{EQ-5D}_{exp}) / \text{EQ-5D}_{sd}\} \qquad \ldots. \ (\text{I})$$

Where:

EQ-$5D_{obs}$ is the observed value of EQ-5Dindex for an individual respondent
EQ-$5D_{exp}$ is the mean EQ-$5D_{index}$ for an individual of the same age/gender
EQ-$5D_{sd}$ is the standard deviation of that expected mean EQ-D_{index}

F5. When this standard transformation is applied to the HSE(2003) survey it yields a mean of 1 and a standard deviation of 1.0. A summary measure of population health (SMPH) can be constructed by computing the mean EQ-5D* for a given group of n individuals whose normative EQ-$5D_{index}$ values are known, that is SMPH = $\sum$ (EQ-5D*) / n.

F6. When applied to subgroups of interest this index takes a value greater than 1 where health status is higher than that of an equivalent normative age/gender sample of the target comparative population. The index is lower than 1 where that health status is poorer.

F7. The SMPH index values for the four Northern Ireland Health Boards and the whole Northern Ireland survey is given in Table F.1

Table F.1 : Standardised summary population health by Health Board

Health Board	***Valid N***	***Mean***	***Standard Error of Mean***
EHSSB	674	0.809	0.052
NHSSB	396	0.991	0.055
SHSSB	333	1.107	0.052
WHSSB	348	1.045	0.055
ALL	1,952	0.959	0.026

F8. The SMPH index for the Northern Ireland survey data is 0.959 - indicative of a health status that is some 4% lower than that of an equivalent population group resident in England.

Table F.2 : Standardised summary population health by Strategic Health Authority (sorted by SMPH index)

Strategic Health Authority	***Mean***	***Count ****
Dorset and Somerset	1.186	407
Thames Valley	1.157	703
Surrey and Sussex	1.150	827
North West London	1.109	542
South West Peninsula	1.097	528
Norfolk, Suffolk and Cambridgeshire	1.094	732
North and East Yorkshire and Northern Lincolnshire	1.087	524
Essex	1.082	595
Hampshire and Isle of Wight	1.068	528
Bedfordshire and Hertfordshire	1.065	586
North Central London	1.059	269
South West London	1.049	364
Leicestershire, Northamptonshire and Rutland	1.039	491
Avon, Gloucestershire and Wiltshire	1.011	667
West Midlands South	1.011	585
Kent and Medway	.965	449
Shropshire and Staffordshire	.956	543
West Yorkshire	.950	657
South East London	.949	370
Trent	.945	1,040
Birmingham and the Black Country	.922	678
Cumbria and Lancashire	.918	682
Greater Manchester	.909	878
Cheshire & Merseyside	.862	764
County Durham and Tees Valley	.860	473
North East London	.844	543
South Yorkshire	.825	372
Northumberland, Tyne & Wear	.807	522

* The number of observations per PCT recorded in the HSE(2003) survey

F9. The corresponding SMPH statistic computed for Strategic Health Authorities (SHA) using the HSE(2003) survey data are listed in Table F.2. The lowest SHA value (Northumberland, Tyne and Wear) corresponds to the value recorded for Eastern HB. The 4th highest SMPH index (North London) corresponds to that recorded for Southern HB. Three SHAs record SMPH index values greater than the best recorded for a Health Board. Given that that the managed population of an SHA is more likely to approximate the total Northern Ireland population rather than that of the individual Health Boards, a fairer comparison might be made by locating the Northern Ireland SMPH value within those seen in Table F.2. On this basis, Northern Ireland equates with Kent and Medway, which is ranked 16/28 amongst SHAs.

Annex G

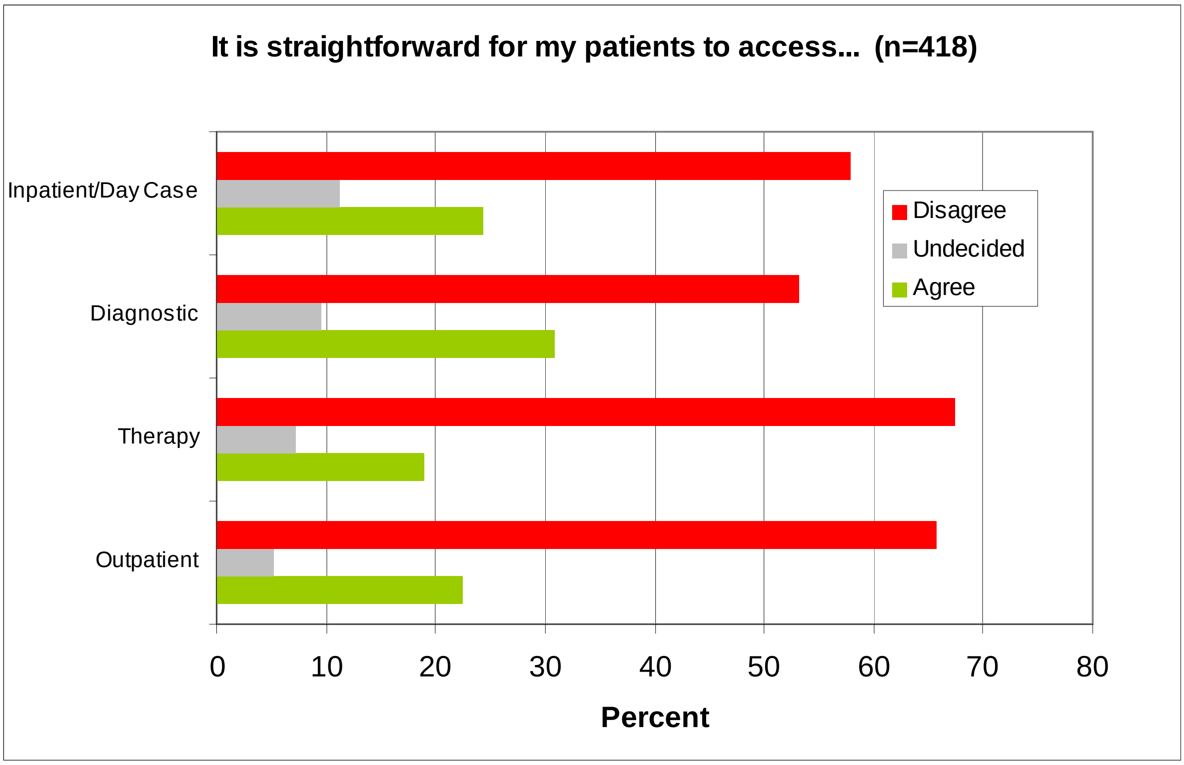
Survey of General Practitioner views and experience of waiting lists and times in Northern Ireland

As part of this Review's investigation, a special survey was carried out by the Review team of GPs experiences and views of waiting times and lists. The questionnaire used was adapted from one used by the National Audit Office in Wales, for whom we are grateful for advice on the survey.

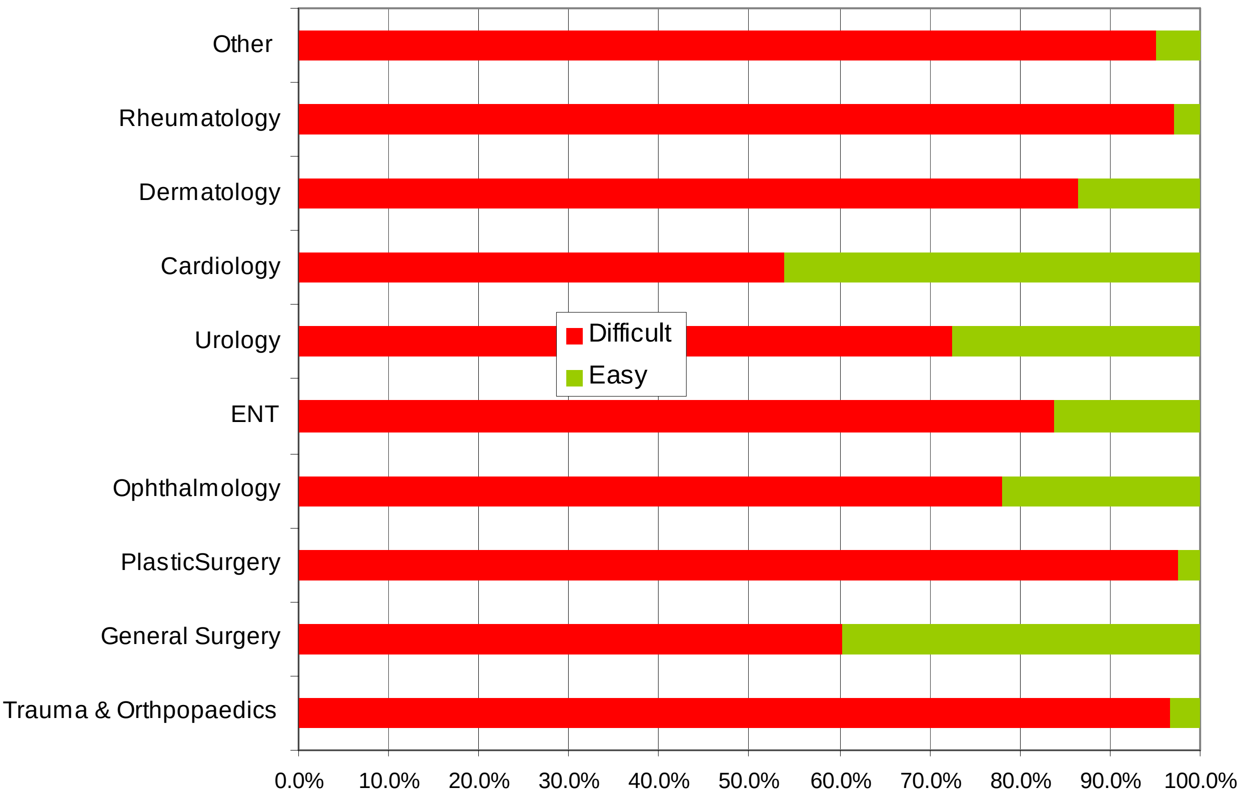
Over 400 GPs returned completed surveys - representing 39% of the total number practising in Northern Ireland.

Here we present a basic descriptive analysis of the results. We have not included additional written comment received by GPs. These will be available at a later date.

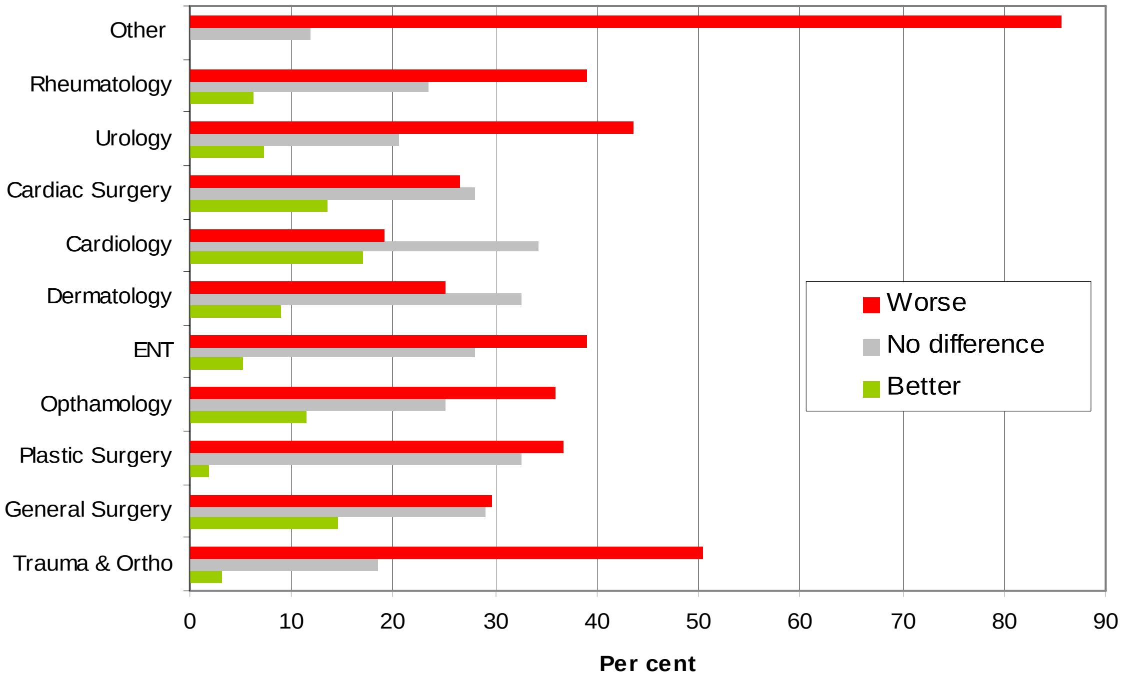
A: Ease of access



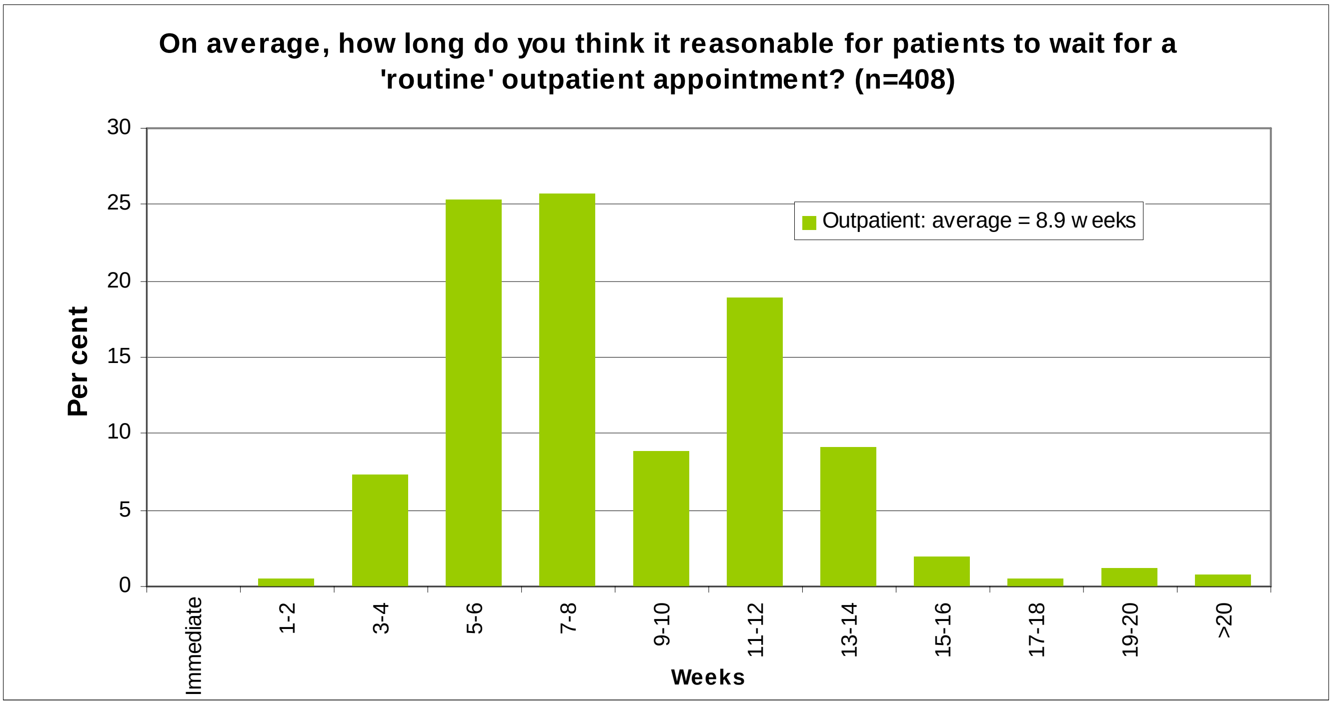
How difficult or easy is it to access particular specialties? (n=418)

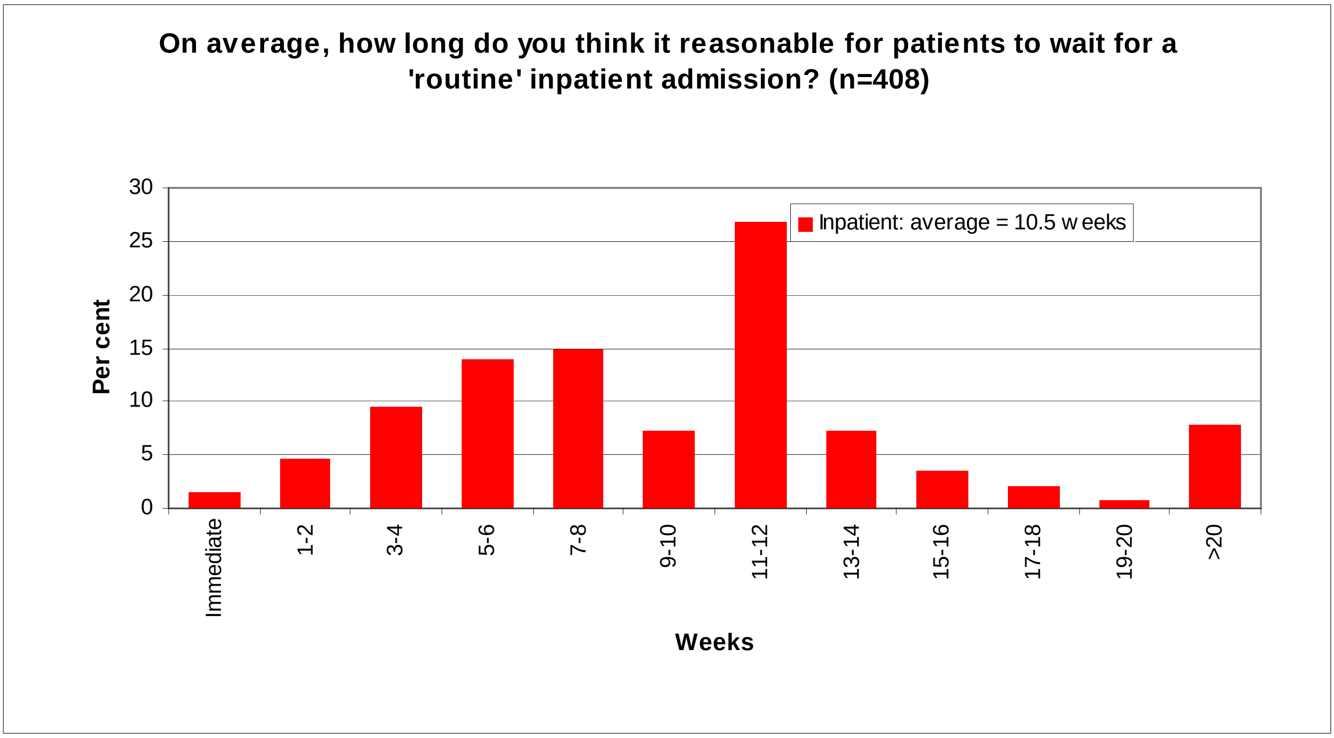


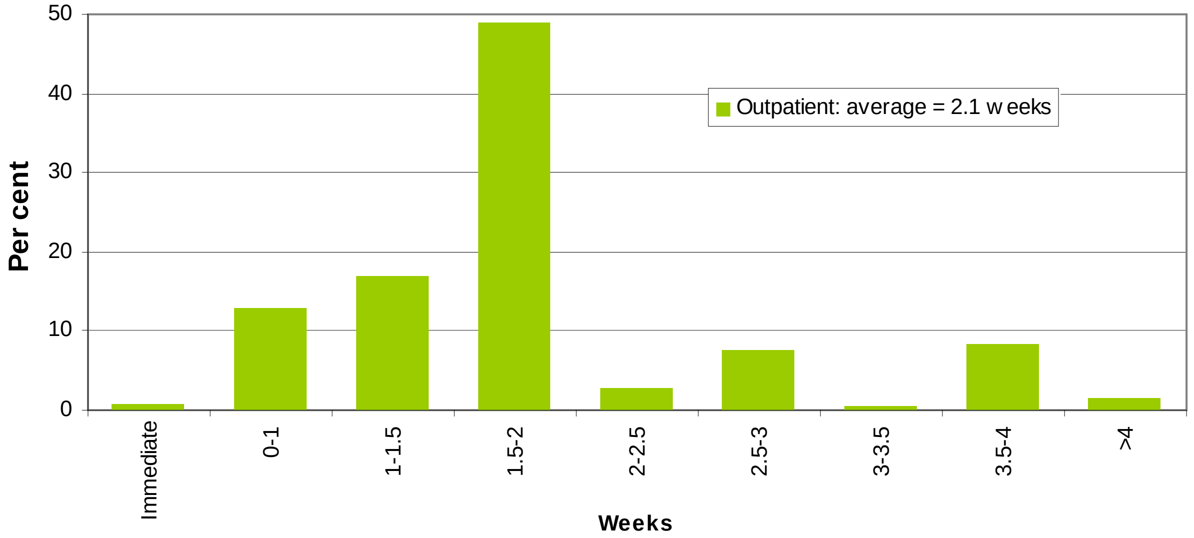
How much have waiting times for inpatient/day cases changed over the last two years? (n=418)



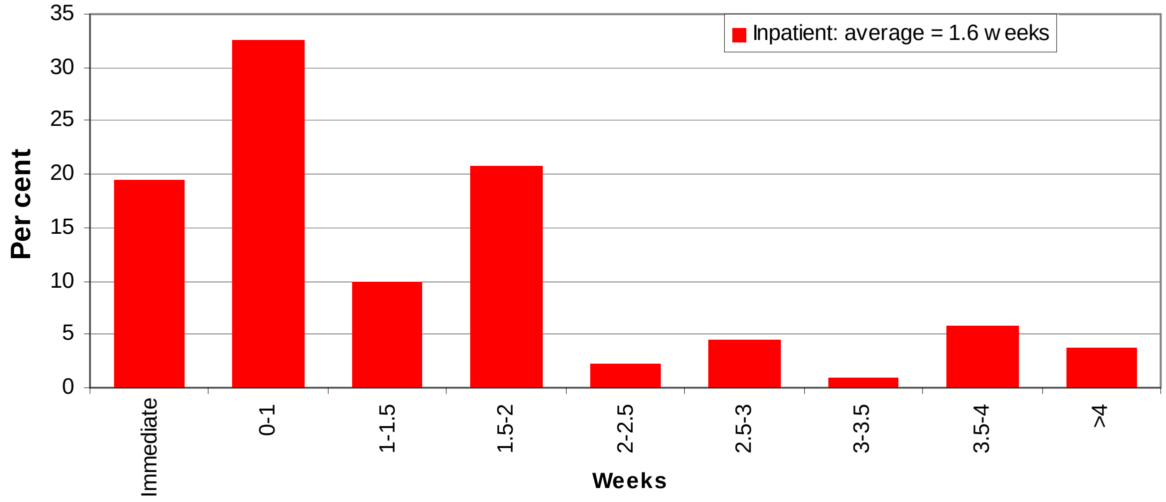
B: ‘Reasonable’ waiting times





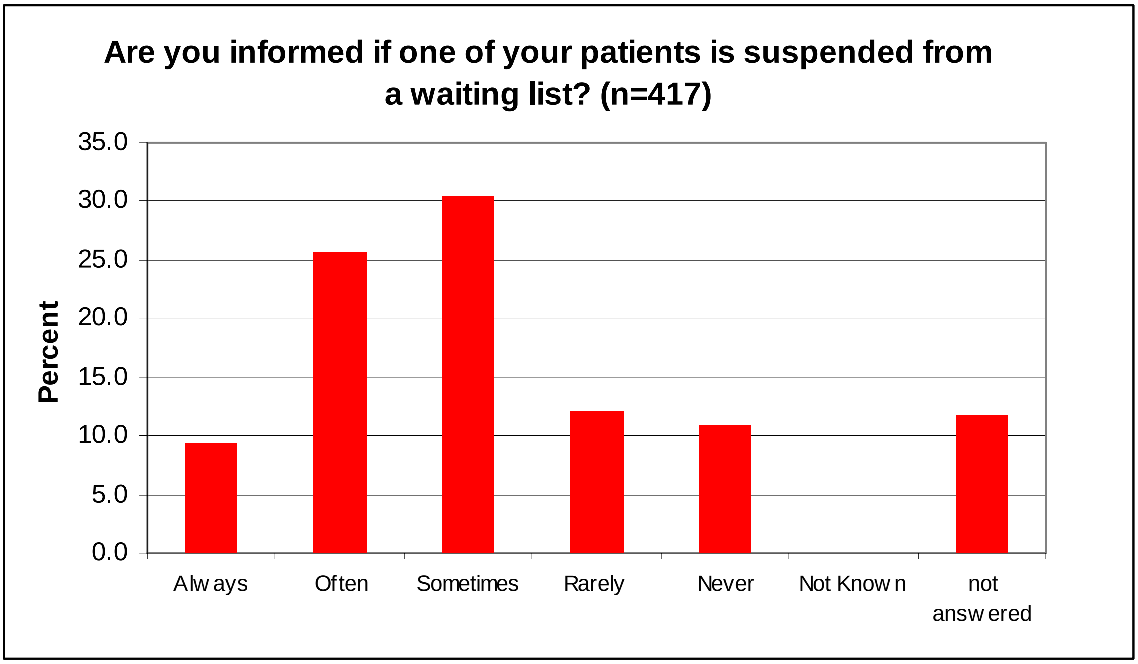


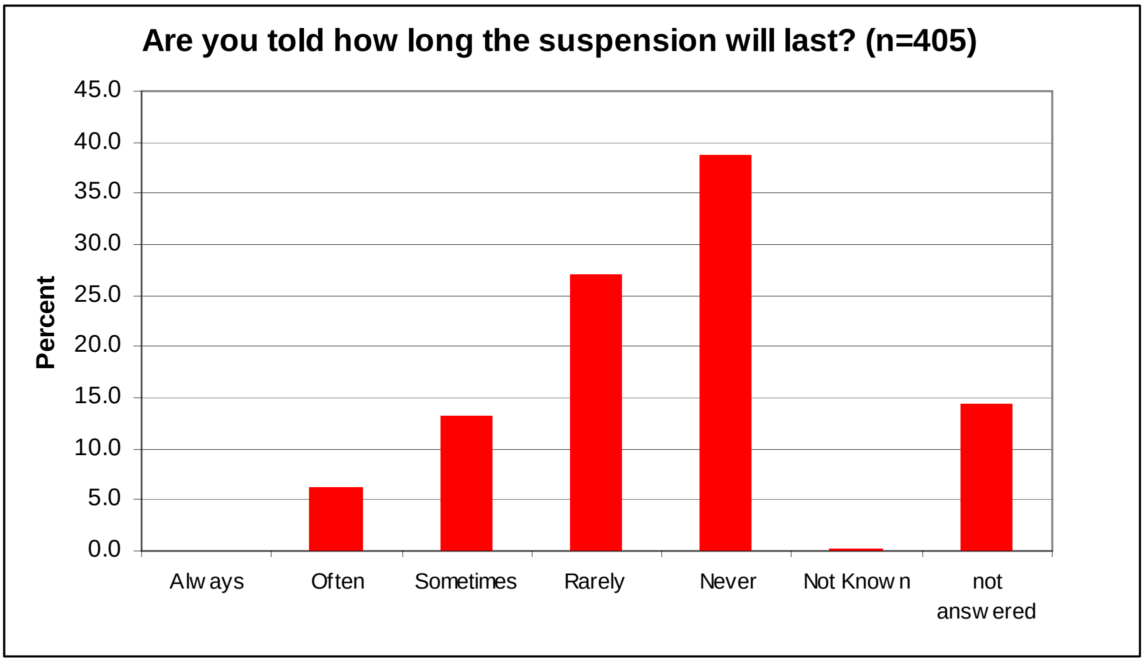
On average, how long do you think it reasonable for patients to wait for an 'urgent' outpatient appointment? (n=408)

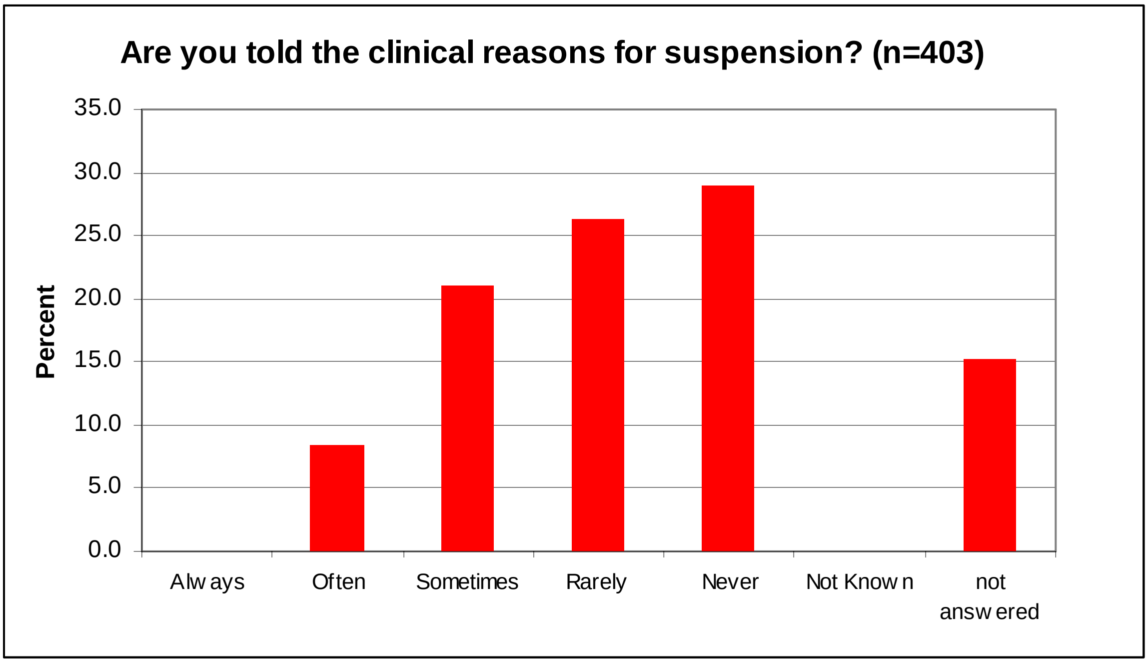


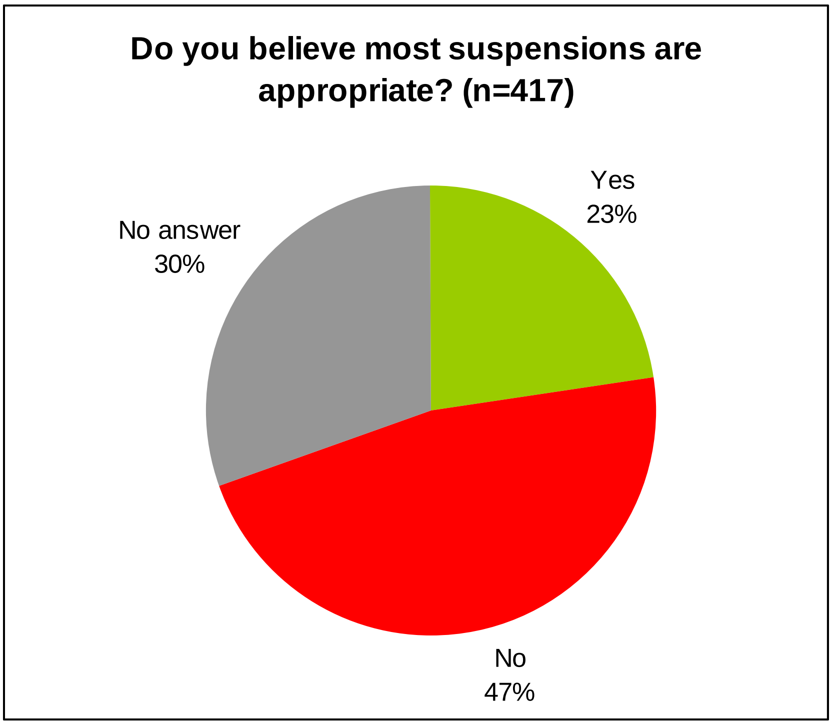
On average, how long do you think it reasonable for patients to wait for an 'urgent' inpatient admission? (n=408)

C: Suspensions from lists

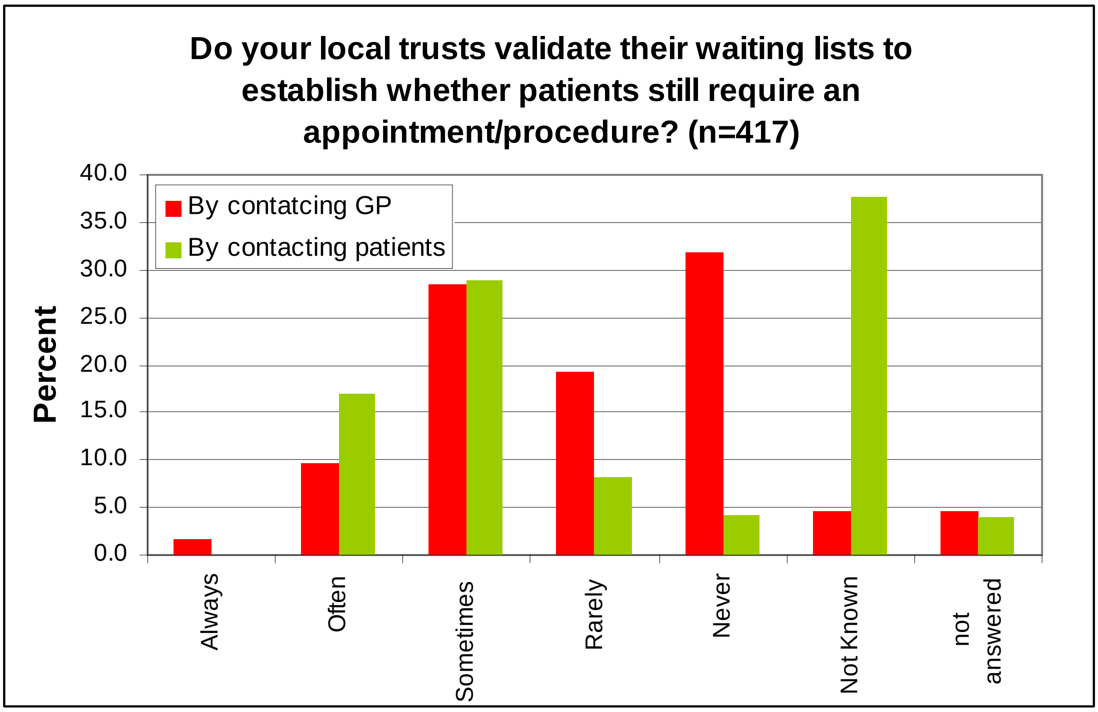




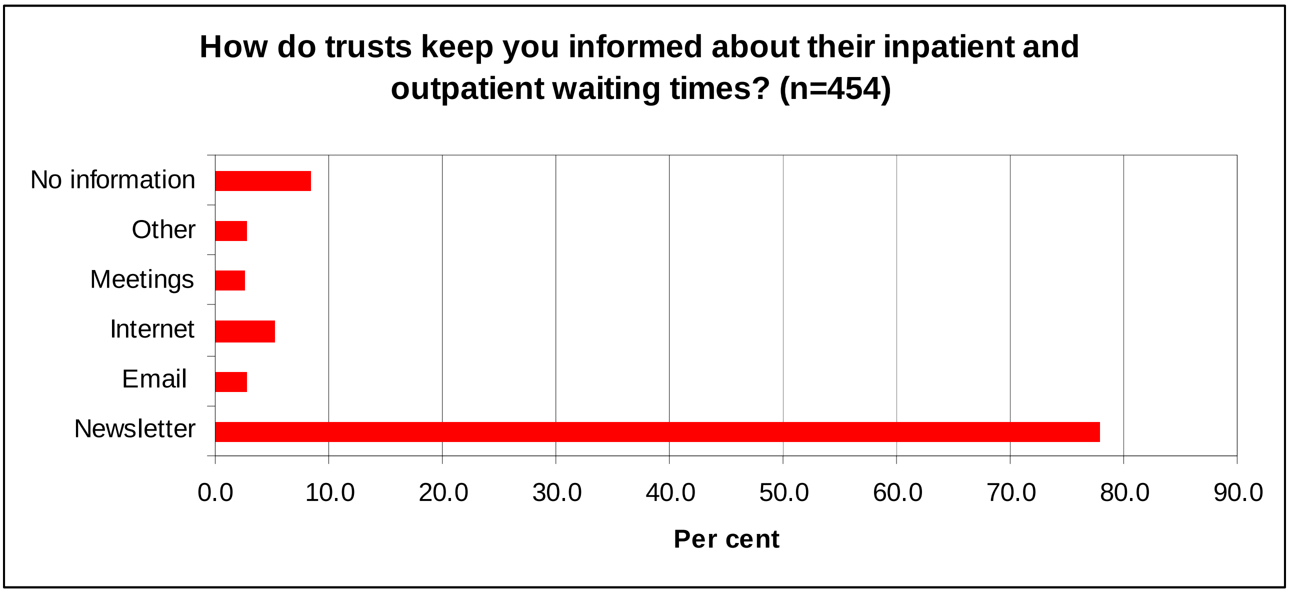

Are you told the clinical reasons for suspension? (n=403)
Percent
35.0
30.0
25.0
20.0
15.0
10.0
5.0
0.0
Always
Often
Sometimes
Rarely
Never
Not Known
not answered

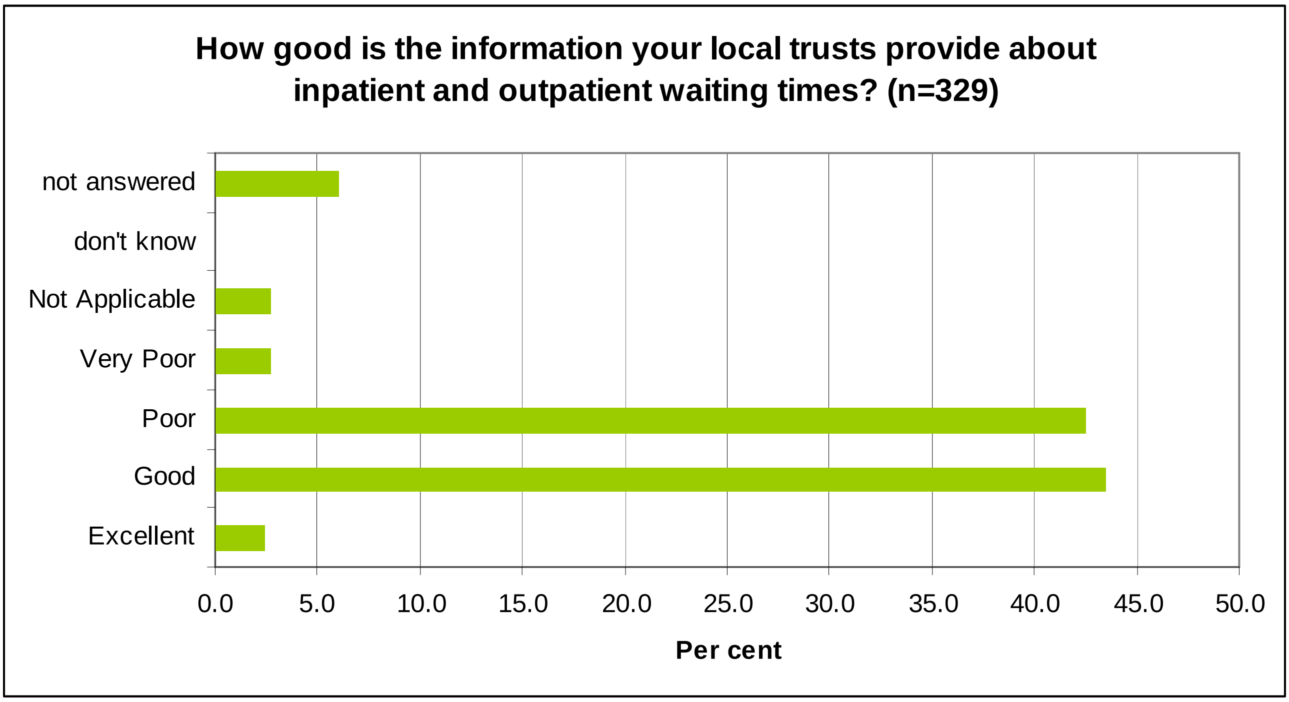

Do you believe most suspensions are appropriate? (n=417)
Yes
23%
No answer
30%
No
47%

D: Validation of waiting lists

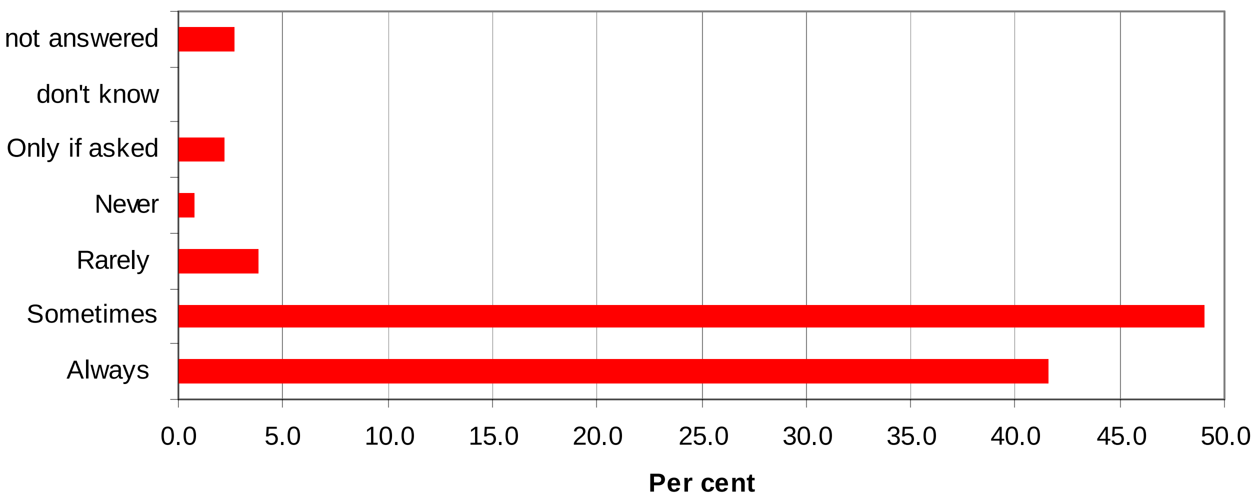


E: Information about waiting

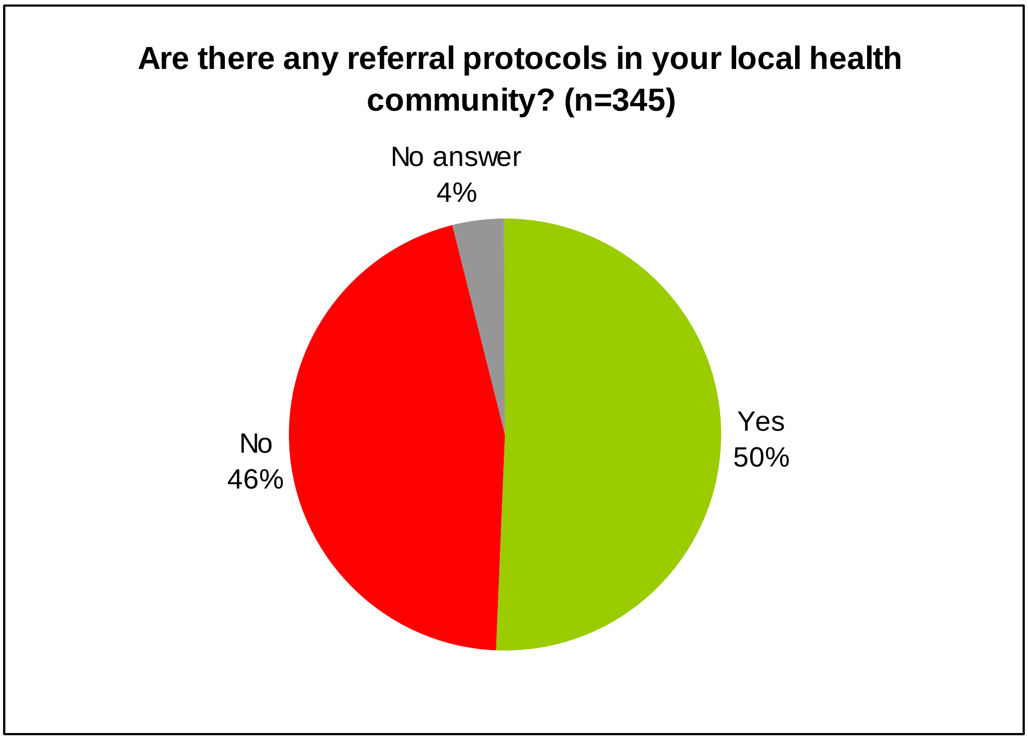


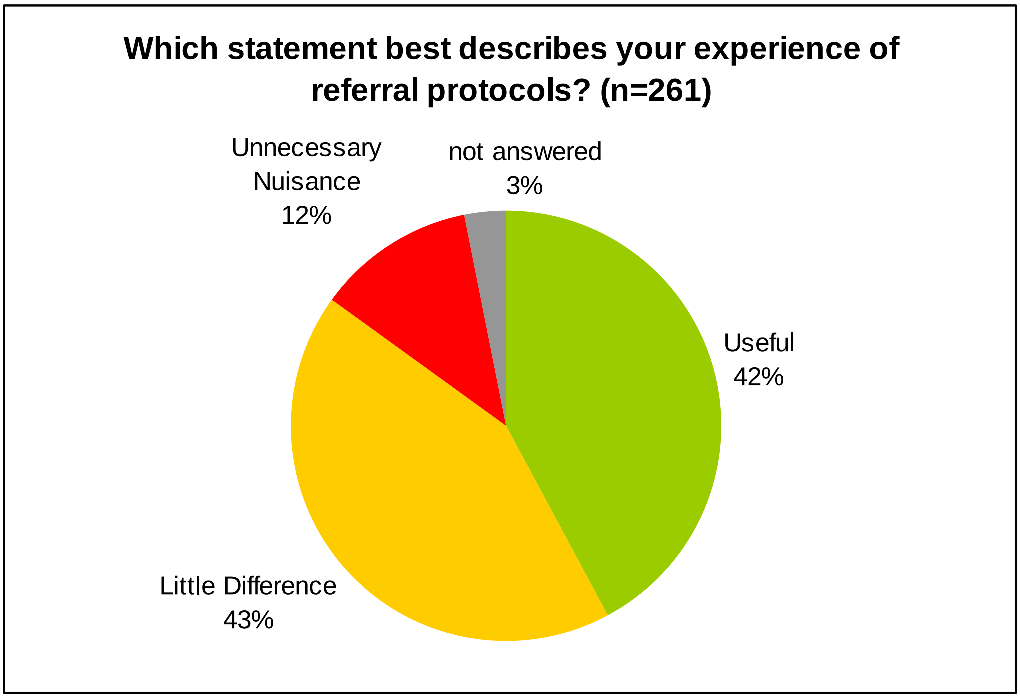


When referring for specialist consultation, do you tell your patients how long they are likely to wait?



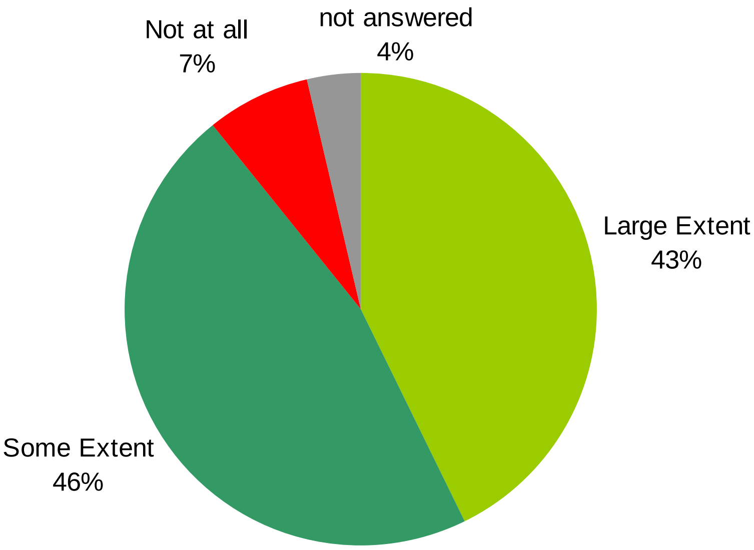
F: Referral protocols



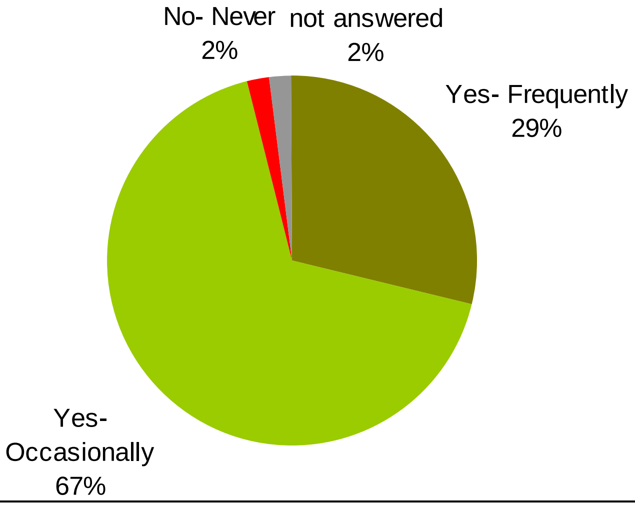


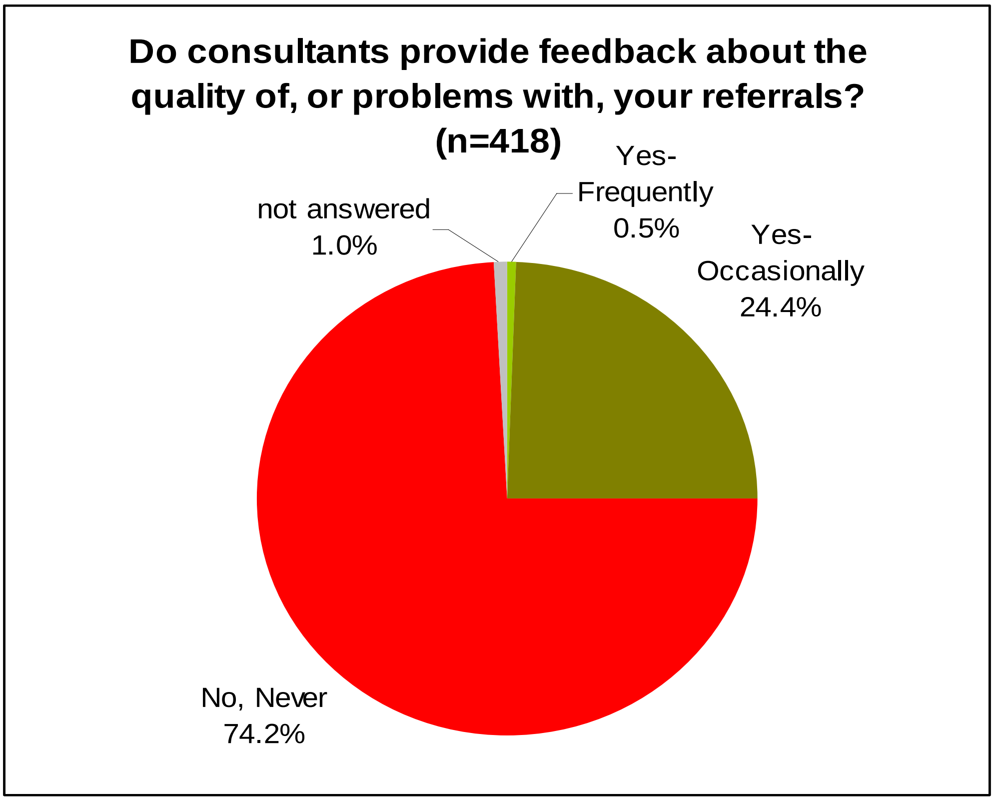
G: Referral decisions

To what extent do waiting times influence your referral decisions? (417)



Do you ever contact a consultant directly in order to have a particular patient treated as a higher priority? (n=417)




Do consultants provide feedback about the quality of, or problems with, your referrals? (n=418)
Yes- Frequently 0.5%
not answered 1.0%
Yes- Occasionally 24.4%
No, Never 74.2%

Annex: H

PERFORMANCE MANAGEMENT ARRANGEMENTS

Description supplied by the DHSPSS:

Background

H1. In recent years, the Department has given priority to ensuring the development of effective arrangements for managing and monitoring service performance in the HPSS. In line with the Secretary of State's *Priorities and Budget* and the Department's Public Service Agreement (PSA) and Business Plan, the Department's main annual planning document for the HPSS is *Priorities for Action*. It translates the PSA into an annual working agenda for the HPSS which must be implemented in a context of financial stability.

Priority Setting and Performance Assessment

H2. On foot of *Priorities for Action*, Boards and Trusts are required to submit Health and Wellbeing Investment Plans and Trust Delivery Plans respectively, detailing how they intend to deploy their resources to meet the identified priorities. A range of measures are in place to monitor their progress against these plans and to provide a clear line of accountability to the Minister and Department. These include annual meetings at Ministerial level with each of the Boards, which provide an opportunity to review the delivery of services in the preceding year, to focus on priority areas for the year in question and to discuss key challenges facing the service.

H3. Departmental officials also conduct a series of progress review meetings with Boards and Trusts during the year, at which quarterly reports detailing progress against targets in *Priorities for Action* are reviewed.

H4. Earlier this year, the Department began a review of performance arrangements in place in the rest of the UK and elsewhere to inform the development of a new high-level performance assessment and reporting framework for the HPSS. The objectives of the framework will include:

- the broadening of the performance focus to embrace the totality of investment in the HPSS;
- the establishment of credible baselines for benchmarking across key areas of financial, organisational and clinical and social care performance; and
- the identification of areas for performance improvement and the development of suitable targets.

H5. Work to date has identified a pool of potential performance indicators, which are currently being evaluated by the Department. It is planned to bring forward proposals for Ministerial consideration in the near future.

Improving Standards

H6. The Department is at present implementing a programme of legislative and organisational change designed to address unacceptable variations in standards of treatment and care and to raise the quality of service provision. This includes:

- placing a statutory duty of quality on Boards and Trusts which will underpin accountability at local level for the quality of services. This duty has been in place since April 2003;
- devising minimum standards of care against which services will be inspected and monitored in the future. A range of standards are currently being developed in preparation for public consultation from autumn 2004; and
- the creation of a new and independent HPSS Regulation and Improvement Authority. The Authority, which is currently being established, will be operational from April 2005 and will be responsible for regulating services, conducting reviews and undertaking inspections.

Governance

H7. In March 2002, the Department adopted the internationally-recognised risk management standard AS/NZS 4360:1999 (already in use in the NHS in England) for itself and all of its associated bodies. The Department sees the adoption of a single model for risk management as an important step towards providing the right environment for the development of effective controls for the range of risks facing the HPSS.

H8. Controls assurance standards supplement this system of risk management by focusing on key areas of risk and providing HPSS bodies with a vehicle to report the extent to which those risk are being managed effectively. An initial six standards were published in 2003/04 and HPSS bodies are due to submit compliance reports against these standards in May 2004. A further 15 standards are being developed.

H9. In addition, the Department has been promoting the development of clinical and social care governance as a framework through which HPSS bodies are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment where excellence in clinical and social care will flourish. This process will be facilitated and supported by a Clinical and Social Care Governance Support Team.

Annex: I

PERFORMANCE MANAGEMENT ARRANGEMENTS

Selected extracts from 2004 Board/DHSPSS Annual Accountability Review meetings:

Northern Board

‘The Board reflected that the continued development of good communication between the Department and the HPSS helped make Priorities for Action a successful way of establishing and pursuing key priorities.’

‘The Department emphasised the continuing importance of action to reduce waiting lists and invited the Board to comment on its ability to meet the waiting list targets set out in Priorities for Action. The Board pointed to the value of central drive by the Department and urged consistency of focus on this [waiting times] area with trusts but said that it thought the targets were achievable, provided, of course, that trusts can deliver their part of the agenda. Given joint accountabilities for delivering the waiting list agenda, the Department encouraged the Board to continue to work collaboratively with trusts to effect improvements in this area.’

Western Board

‘The Department asked the Board to comment on its performance. The Board highlighted 3 areas where progress had been difficult, the first of these was in relation to waiting lists where the total numbers of people had increased, causing the Board to miss its target for reduction in numbers waiting by 27. The Board explained that problems had arisen at Altnagelvin where efforts to tackle outpatient waiting in ENT and ophthalmology had had a knock-on effect on inpatient waiting numbers. The Department emphasised the need to maintain focus and momentum on hospital waiting and noted the efforts now being made by the Board and trust to tackle this problem in 2004/5.’ [This is the full extent of minted discussions about waiting lists/times performance for this Board]

Southern Board

The Department underlined that the HPSS must aspire to the standards being delivered in England and Wales and emphasised that the Board and local trusts should not aim to simply satisfy the targets this year but should be creative in the use of resources to deliver the best outcome possible on waiting times and numbers. The Board undertook to work to exceed the targets wherever that was possible and provided the meeting with a copy of an internal Board report on the Secondary Care targets contained in Priorities for Action.’

Department of
Health, Social Services
and Public Safety

An Roinn
Sláinte, Seirbhísí Sóisialta
agus Sábháilteachta Poiblí

www.dhsspsni.gov.uk

The Quality Standards for Health and Social Care

SUPPORTING GOOD GOVERNANCE AND BEST PRACTICE IN THE HPSS

March 2006

FOREWORD BY THE MINISTER

The people of Northern Ireland are entitled to the highest standards of health and social care. Having standards in place to ensure that people have the right care wherever they live in Northern Ireland is a fundamental principle of reform and modernisation of the health and social care system.

I am committed to putting patients, clients and carers first. The *Quality Standards for Health and Social Care* set out the standards that people can expect from Health and Personal Social Services (HPSS). In developing these standards, my aim is to raise the quality of services and to improve the health and social wellbeing of the people of Northern Ireland. At the heart of these standards are key service user and carer values including dignity, respect, independence, rights, choice and safety.

The standards have five key quality themes:

- Corporate leadership and accountability of organisations;
- Safe and effective care;
- Accessible, flexible and responsive services;
- Promoting, protecting and improving health and social well-being; and
- Effective communication and information.

The publication of the quality standards is an important milestone in the process of putting patients first. They will be used by the new Regulation and Quality Improvement Authority to assess the quality of care provided by the HPSS. The new Authority will be looking to see how the HPSS provide quality services and will be reporting their findings both to the Department and to the public.

Given the rapidly changing environment in which the HPSS now operates including changes arising from the Review of Public Administration, it is important that these standards do not become outdated or serve to stifle innovation. Therefore, the standards will be reviewed by the end of 2008.

SHAUN WOODWARD MP
Minister for Health, Social Services and Public Safety

CONTENTS PAGE

Section 1: Introduction to the Development of Standards

1.1 Introduction

Almost 95% of the population of Northern Ireland makes contact with health and social services on an annual basis. This contact may be through primary care services, community care services or through hospitals. In all of these contacts, people are entitled to the highest standards of health and social care.

This document sets out clearly for the public, service users and carers, and those responsible for the commissioning, planning, delivery, and review of services, the quality standards that the Department considers people should expect from Health and Personal Social Services (HPSS). It represents a significant step in the process of placing the needs of the service user and carer, and the wider public, at the centre of planning, delivery and review of health and social care services.

1.2 Background to the development of standards

Quality improvement is at the forefront of the development of health and social care services in Northern Ireland. These improvements are centred around five main areas, which are an integral part of modernisation and reform:

- setting of standards – to improve services and practice;
- improving governance in the HPSS - in other words, the way in which the HPSS manages its business;
- improving the regulation of the workforce, and promoting staff development through life-long learning and continuous professional development;
- changing the way HPSS organisations are held to account for the services they provide; and
- establishing a new, independent body to assess the quality of health and social care.

The consultation document “Best Practice – Best Care”, published in April 2001, sets out the detail of this framework to improve the quality of care. This included links to national standard setting bodies such as the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE).

1.3 Improving governance in health and social care

The outcome of the Review of Public Administration, announced in November 2005, signalled major changes to the structure and functions of HPSS organisations. Regardless of these changes there remains a statutory duty of quality on HSS Boards and Trusts. This means that each organisation has a legal responsibility for satisfying itself that the quality of care it commissions and/or provides meets a required standard. This requirement is just as important as the responsibility to demonstrate financial regularity and propriety. Organisations must ensure that there are visible and rigorous structures, processes, roles and responsibilities in place to plan for, deliver, monitor and promote safety and quality improvements in the provision of health and social care. This process is known as *Governance*.

1.4 The setting of standards

In addition to drawing on national and professional standards, a range of local standards is being developed to enhance governance arrangements in the HPSS. These include controls assurance standards, so that by 2006-07, there will be a comprehensive set of specific assurance standards, which the HPSS can use to assess compliance against the required attainment levels. In addition, a number of care standards have been developed to facilitate the inspection and regulation of specific health and social care services provided by the HPSS and the independent sector. These care standards are specified in legislation and will be inspected, regulated and monitored by a new organisation called the Health and Personal Social Services Regulation and Improvement Authority (the Regulation and Quality Improvement Authority - RQIA).

The development of the *Quality Standards for Health and Social Care*, as outlined in this document, is intended to complement standards already issued or currently in development. Consequently, evidence of compliance with existing or new standards, such as professional standards, charter standards, controls assurance and/or care standards will form part of the evidence of practitioner or organisational commitment to these new quality standards.

1.5 What is a standard?

A standard is a level of quality against which performance can be measured. It can be described as ‘essential’- the absolute minimum to ensure safe and effective practice, or ‘developmental’, - designed to encourage and support a move to better practice. The *Quality Standards for Health and Social Care*, which are contained in this document, are classed as essential.

Given the rapidly changing environment in which the HPSS operates, it is important that standards do not become outdated or serve to stifle innovation.

To prevent this, standards need to be regularly reviewed and updated. It will be the Department's responsibility, drawing on the best evidence available, including advice, reports and/or information from the RQIA, to keep the quality standards under consideration, with a formal review being completed by the end of 2008.

1.6 Why are standards important?

Raising and maintaining the quality of services provided by the HPSS is a major objective for all involved in the planning, provision, delivery and review of health and social care services. Currently, there remains unacceptable variation in the quality of services provided, including timeliness of delivery and ease of access.

In order to improve the quality of these services, change is needed, underpinned and informed by a more cohesive approach to standards development.

Standards:

- give HPSS and other organisations a measure against which they can assess themselves and demonstrate improvement, thereby raising the quality of their services and reducing unacceptable variations in the quality of services and service provision;

- enable service users and carers to understand what quality of service they are entitled to and provide the opportunity for them to help define and shape the quality of services provided by the HPSS and others;

- provide a focus for members of the public and their elected representatives, to consider whether their money is being spent on efficient and effective services, and delivered to recognised standards;

- help to ensure implementation of the duty the HPSS has in respect of human rights and equality of opportunity for the people of Northern Ireland; and

- promote compliance, and underpin the regulation and monitoring of services to determine their quality and safety and to gauge their continuous improvement.

By promoting integration, these *Quality Standards for Health and Social Care* will contribute to the implementation of clinical and social care governance in the HPSS and will be used by HPSS and other organisations, service users and carers, the wider public and the RQIA to assess the quality of care provision.

1.7 The five quality themes

There are five quality themes on which the standards have been developed to improve the health and social well-being of the population of Northern Ireland. These themes have been identified through consultation with service users, carers and HPSS staff and through a review of standards developed elsewhere at local, national and international level.

The five quality themes are:

1. Corporate Leadership and Accountability of Organisations;
2. Safe and Effective Care;
3. Accessible, Flexible and Responsive Services;
4. Promoting, Protecting and Improving Health and Social Well-being; and
5. Effective Communication and Information.

1.8 Assessing quality

The RQIA was established by the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003 and began work on 1 April 2005. It has two main functions:

- inspection and regulation of specified health and social care services provided by the HPSS and the independent sector; and

- inspection and review of the services provided by the HPSS in Northern Ireland.

The RQIA has a general duty to encourage improvements in the quality of services commissioned and provided by HPSS and other organisations. It will promote a culture of continuous improvement and best practice through inspection and review of clinical and social care governance arrangements.

The RQIA has taken over responsibility for the registration, inspection and regulation of providers of care, for example, residential care, nursing homes and day care facilities. On a phased basis, the RQIA will assume further responsibilities over the coming years, including reporting on the quality of care provided by the HPSS. Where serious and/or persistent clinical and social care governance problems come to light, it will have a key role to play, in collaboration with other regulatory and inspectoral bodies, in the investigation of such incidents. It will report on its findings to the Department and to the public.

1.9 How will the standards be used to measure quality?

The RQIA, in conjunction with the HPSS, service users and carers, will agree how the standards will be interpreted to assess service quality. It is envisaged that specific tools will be designed to allow the RQIA to measure that quality and to assist the HPSS in assessing themselves. Once developed, not only will these tools assess HPSS structures and processes but they will also contribute to the assessment of clinical and social care outcomes.

Whilst it is for the RQIA to provide guidance on what assessment methods it will use, it is recognised that collecting the evidence to demonstrate that relevant standards have been successfully achieved may be a time consuming process for the HPSS. Therefore, information that is currently compiled on existing standards will also be able to be used to contribute to the demonstration of achievement for these standards.

The RQIA will commence reviewing clinical and social care governance within the HPSS in 2006/07, using the five themes contained within this document. RQIA will report on the quality of care provided by the HPSS following its review. This approach will promote quality improvement across organisations.

Section 2: Values and Principles Underpinning the Standards

2.1 Introduction

There are three key premises, which underpin these quality standards and are central to all aspects of planning, provision, delivery, review and improvement of the HPSS. They are that:

- people in receipt of services should be actively involved in all decisions affecting their lives and should fully contribute to any planning for, delivery and evaluation of, services;
- clinical and social care governance in the HPSS must take account of the organisational structures, functions and the manner of delivery of services currently in place. Clinical and social care governance must also apply to all services provided in community, primary, secondary and tertiary care environments;
- service users and carers should be fully valued by HPSS staff who, in turn, should be valued by service users, carers and others.

2.2 The values underpinning the Standards

The quality of a service provided is dependent on managers and HPSS staff basing their practice on the following values and principles; these complement those already outlined in the care standards for independent agencies, establishments and certain other services provided by HPSS organisations.

They are:

DIGNITY AND RESPECT	The uniqueness and intrinsic value of the individual is acknowledged and each person is treated with dignity and respect. This is applicable to service users, carers, staff and others who come in contact with services.
INDEPENDENCE	A balance between the promotion of independence and risk taking is needed. Service users have as much control as possible over their lives. Service users are informed about risk whilst being protected against unreasonable risks.
PROMOTION OF RIGHTS	In the context of services delivered to them, the individual and human rights of service users are promoted and safeguarded. Where necessary, appropriate advocacy arrangements are put in place.
EQUALITY AND DIVERSITY	Equality of opportunity and positive outcomes for service users and staff are promoted; their background and culture are valued and respected.
CHOICE AND CAPACITY	Service users are offered, wherever possible, according to assessed need and available resources, the opportunity to select independently from a range of options based on clear and accurate information, which is presented in a manner that is understood by the service user and carer.
PRIVACY	Service users have the right to be free from unnecessary intrusion into their affairs and there is a balance between the consideration of the individual's safety, the safety of others and HPSS organisational responsibilities.
EMPOWERMENT	Service users are enabled and supported to achieve their potential in health and social well-being. Staff are supported and developed to realise their ability and potential.
CONFIDENTIALITY	Information about service users and staff is managed appropriately and everyone involved in the service respects confidential matters.
SAFETY	Every effort is made to keep service users, staff and others as safe as is possible. In all aspects of treatment and care, service users are free from exploitation, neglect or abuse.

2.3 The principles underpinning the Standards

The following principles are fundamental to the development of a quality service.

PUBLIC AND SERVICE USER INVOLVEMENT	The views and experiences of service users, carers, staff and local communities are taken into account in the planning, delivery, evaluation and review of services. Service users and carers, wherever possible, are involved in, and informed about, decisions made when they seek access to or receive services during their treatment or care.
SAFETY AND EFFECTIVENESS	Systems are in place to ensure that the safety of service users, carers, staff and the wider public, as appropriate, underpin all aspects of health and social care delivery. For example, the imperative to protect children and vulnerable adults may take precedence over the specific wishes of the service user and their carers. In addition, the protection of staff may need to be balanced with the specific wishes of service users, carers, families and friends. Quality systems are in place to enable staff to play a full and active role in providing effective and efficient health and social care services for all who use these services. Staff are fully supported, regularly supervised and appropriately trained and educated, to provide safe and effective health and social care services.
ROBUST ORGANISATIONAL STRUCTURES AND PROCESSES	Robust organisational structures and processes are in place, which are regularly reviewed to promote safe and effective delivery of care. Timely information is shared and used appropriately to optimise health and social care.
QUALITY of SERVICE PROVISION	Policies, procedures and activities are in place to encourage and enable continuous quality improvement. Service developments and provision are based on sound information and knowledge of best practice, as appropriate.

Section 3: Format of the Standards

3.1 The five quality themes

The five quality themes are applicable to the whole of the HPSS, including those services, which are commissioned or provided by HPSS organisations and family practitioner services. They are underpinned by the duty of quality on HSS Boards and Trusts. Where care is commissioned outside Northern Ireland, commissioners must ensure that the quality of care is commensurate with these and other associated standards.

The five quality themes, encompassing the standards, are set out in sections four to eight of this document. These are:-

- Corporate Leadership and Accountability of Organisations (Section 4);
- Safe and Effective Care (Section 5);
- Accessible, Flexible and Responsive Services; (Section 6);
- Promoting, Protecting and Improving Health and Social Well-being (Section 7); and
- Effective Communication and Information (Section 8).

3.2 Format of the standards

Each theme has a **title**, which defines the area upon which the standard is focused. Then, a **standard statement** will explain the level of performance to be achieved. The reason why the standard is seen to be important will be covered by the **rationale**. The standard statement will then be expanded into a series of **criteria**, which will provide further detail of areas for consideration by the HPSS and by RQIA.

Section 4: Corporate Leadership and Accountability of Organisations (Theme 1)

4.1 Standard Statement

The HPSS is responsible and accountable for assuring the quality of services that it commissions and provides to both the public and its staff. Integral to this is effective leadership and clear lines of professional and organisational accountability.

4.2 Rationale

The HPSS must provide effective leadership and a clear direction to make the most of its resources (people, skills, time and money), and to deliver high quality services to the public in as safe an environment as is possible. The aim is to ensure a competent, confident workforce and an organisation that is open to learning and is responsive to the needs of service users and carers. This will facilitate staff in the organisation to take individual, team and professional responsibility in order to promote safe, sustainable and high quality services. The organisation needs to maintain and further enhance public confidence.

4.3 Criteria

The organisation:

a) has a coherent and integrated organisational and governance strategy, appropriate to the needs, size and complexity of the organisation with clear leadership, through lines of professional and corporate accountability;

b) has structures and processes to support, review and action its governance arrangements including, for example, corporate, financial, clinical and social care, information and research governance;

c) has processes in place to develop leadership at all levels including identifying potential leaders of the future;

d) actively involves service users and carers, staff and the wider public in the planning and delivery, evaluation and review of the corporate aims and objectives, and governance arrangements;

e) has processes in place to develop, prioritise, deliver and review the organisation's aims and objectives;

f) ensures financial management achieves economy, effectiveness, efficiency and probity and accountability in the use of resources;

g) has systems in place to ensure compliance with relevant legislative requirements;

h) ensures effective systems are in place to discharge, monitor and report on its responsibilities in relation to delegated statutory functions and in relation to inter-agency working;

i) undertakes systematic risk assessment and risk management of all areas of its work;

j) has sound human resource policies and systems in place to ensure appropriate workforce planning, skill mix, recruitment, induction, training and development opportunities for staff to undertake the roles and responsibilities required by their job, including compliance with:

- Departmental policy and guidance;
- professional and other codes of practice; and
- employment legislation.

k) undertakes robust pre-employment checks including:

- qualifications of staff to ensure they are suitably qualified and are registered with the appropriate professional or occupational body;
- police and Protection of Children and Vulnerable Adults checks , as necessary;
- health assessment, as necessary; and
- references.

l) has in place appraisal and supervision systems for staff which support continuous professional development and lifelong learning, facilitate professional and regulatory requirements, and informs the organisation's training, education and workforce development;

m) has a training plan and training programmes, appropriately funded, to meet identified training and development needs which enable the organisation to comply with its statutory obligations; and

n) has a workforce strategy in place, as appropriate, that ensures clarity about structure, function, roles and responsibilities and ensures workforce development to meet current and future service needs in line with Departmental policy and the availability of resources.

Section 5: Safe and Effective Care (Theme 2)

5.1 Standard Statement

Safe and effective care is provided by the HPSS to those service users who require treatment and care. Treatment or services, which have been shown not to be of benefit, following evaluation, should not be provided or commissioned by the HPSS.

5.2 Rationale

A quality service is one which is safe, effective and sustainable. Diminished standards on safety reflect a poor quality of service. The provision of health and social care is complex and will never be one hundred percent error-free. However, more can always be done to avoid injury and harm to service users, from the treatment and care that is intended to help them. This is an integral part of continuous quality improvement. Services must be delivered in a way that appropriately manages risk for service users, carers, staff, the public and visitors. Where an adverse incident has occurred or has been prevented from happening (a near miss), then systems need to be in place to assist individuals and organisations to learn from mistakes in order to prevent a reoccurrence.

It is acknowledged, however, that in some situations, living with a risk can be outweighed by the benefit of having a lifestyle that the individual really wants and values. In such circumstances, risk taking can be considered to be a positive action. Health and social care staff need to work in partnership with service users and carers to explore choices and agree on how risk can be managed and minimised for the benefit of individual service users, carers, families and communities.

The promotion of safe care must be complemented by the provision of effective care. Care should be based on the best available evidence of interventions that work and should be delivered by appropriately competent and qualified staff in partnership with the service user. Systems and processes within organisations should facilitate participation in, and implementation of, evidence-based practice.

This theme of “Safe and Effective Care” has been subdivided into three areas:

- ensuring safe practice and the appropriate management of risk;
- preventing, detecting, communicating and learning from adverse incidents and near misses; and
- promoting effective care.

5.3 Criteria

5.3.1 Ensuring Safe Practice and the Appropriate Management of Risk

The organisation:

a) has effective person-centred assessment, care planning and review systems in place, which include risk assessment and risk management processes and appropriate interagency approaches;

b) acknowledges and promotes the central place that patients, service users and carers have in the prevention and detection of adverse incidents and near misses;

c) has policies and procedures in place to identify and protect children, young people and vulnerable adults from harm and to promote and safeguard their rights in general;

d) promotes effective interagency working in relation to raising awareness of the risk factors associated with abuse, including domestic violence and in the promotion of effective interagency responses;

e) has a safety policy in place which takes account of the needs of service users, carers and staff, the public and the environment; and

f) has properly maintained systems, policies and procedures in place, which are subject to regular audit and review to ensure:

- efficacy and comparability of outcomes in health and social care;
- compliance with professional and other codes of practice;
- effective and efficient procedures for obtaining informed consent for examination, treatment and/or care;
- accurate, timely and consistent recording of care given or services provided and associated outcomes;
- protection of health, welfare and safety of staff;
- awareness raising and staff knowledge of reporting arrangements for adverse incidents and near misses, and whistleblowing arrangements when poor performance and/or unsafe practice in examination, treatment or care comes to light;
- there is choice where food and/or fluid is provided, which reflects cultural and spiritual preferences and that procedures are in place to promote the safe handling of food and a healthy diet;

- safe practice in the selection, procurement, prescription, supply, dispensing, storage and administration of medicines across the spectrum of care and support provided, which complies with current medicines legislation;

- promotion of safe practice in the use of medicines and products, particularly in areas of high risk, for example:
    - intrathecal chemotherapy;
    - blood and blood products;
    - intravenous fluid management;
    - methotrexate;
    - potassium chloride; and
    - anticoagulant therapy.

- risk assessment and risk management in relation to the acquisition and maintenance of medical devices and equipment, and aids and appliances across the spectrum of care and support provided;

- promotion of general hygiene standards, and prevention, control and reduction in the incidence of healthcare acquired infection and other communicable diseases;

- appropriate decontamination of reusable medical devices;

- safe and effective handling, transport and disposal of waste, recognising the need to promote the safety of service users and carers, staff and the wider public, and to protect the environment;

- interventional procedures and/or any new methods undertaken by staff are supported by evidence of safety and efficacy;

- address recommendations contained in RQIA reports (when available), service and case management reviews; and

- participation in and implementation of recommendations contained in local or national enquiries, where appropriate, e.g. National Confidential Enquiries.

5.3.2 Preventing, Detecting, Communicating and Learning from Adverse Incidents and Near Misses

The organisation:

a) has systems and processes in place to prevent, identify, assess and manage and review adverse incidents and near misses across the spectrum of care and support provided;

b) promotes an open and fair culture, rather than one of blame and shame, to encourage the timely reporting and learning from adverse incidents and near misses;

c) has reporting systems in place to collate, analyse and learn from all adverse incidents, and near misses, share knowledge and prevent reoccurrence of adverse incident or near miss; and

d) has systems in place that promote ongoing communication with service users and carers when treatment or care goes wrong, and puts in place an individual care plan to minimise injury or harm.

5.3.3 Promoting Effective Care

The organisation:

a) provides relevant, accessible, information to support and enhance service user and carer involvement in self-management of their health and social care needs;

b) promotes a person-centred approach and actively involves service users and carers in the development, implementation, audit and review of care plans and care pathways;

c) promotes a culture of learning to enable staff to enhance and maintain their knowledge and skills;

d) ensures that clinical and social care interventions are carried out under appropriate supervision and leadership, and by appropriately qualified and trained staff, who have access to appropriate support systems;

e) uses recognised clinical and social care standards and outcomes as a means of measuring health and social care quality;

f) promotes the implementation of evidence based practice through use of recognised standards and guidelines including guidance from the Department, NICE, SCIE and the National Patient Safety Agency (NPSA);

g) has in place systems to promote active participation of staff in evidence based practice, research, evaluation and audit;

h) has systems in place to prioritise, conduct and act upon the findings of clinical and social care audit and to disseminate learning across the organisation and the HPSS, as appropriate;

i) provides regular reports to the organisation's executive and non-executive board directors on clinical and social care governance arrangements and continuous improvement in the organisation; and

j) promotes the involvement of service users and carers in clinical and social care audit activity.

Section 6: Accessible, Flexible and Responsive Services (Theme 3)

6.1 Standard Statement

Services are sustainable, and are flexibly designed to best meet the needs of the local population. These services are delivered in a responsive way, which is sensitive to individual's assessed needs and preferences, and takes account of the availability of resources.

Each organisation strives to continuously improve on the services it provides and/or commissions.

6.2 Rationale

To meet the needs of local communities and to narrow inequalities in health and social well-being, services should take account of the current and anticipated needs of the local community. Service users, carers, front line staff and the wider public should be meaningfully engaged in all stages of the service planning and decision-making cycle. Assessment of need should be undertaken in partnership with the statutory, voluntary, private and community sectors. This should be informed by the collation and analysis of information about the current health and social well-being status of the local population, unmet need, legislative requirements, and evidence of best practice and review of current service provision. Service planning should also take account of local and regional priorities and the availability of resources.

In order to promote systematic approaches to the development of responsive, flexible and accessible services for the local population and for individuals, this theme has been sub-divided into two main areas:

- service planning processes; and
- service delivery for individuals, carers and relatives.

6.3 Criteria

6.3.1 Service Planning Processes

The organisation:

a) has service planning processes which promote an equitable pattern of service provision or commissioning based on assessed need, having regard to the particular needs of different localities and people, the availability of resources, and local and regional priorities and objectives;

b) integrates views of service users, carers and local communities, and front line staff into all stages of service planning, development, evaluation and review of health and social care services;

c) promotes service design and provision which incorporates and is informed by:

  - information about the health and social well-being status of the local population and an assessment of likely future needs;

  - evidence of best practice and care, based on research findings, scientific knowledge, and evaluation of experience;

  - principles of inclusion, equality and the promotion of good relations;

  - risk assessment and an analysis of current service provision and outcomes in relation to meeting assessed needs;

  - current and/or pending legislative and regulatory requirements;
  - resource availability; and

  - opportunities for partnership working across the community, voluntary, private and statutory sectors.

d) has service planning and decision-making processes across all service user groups, which take account of local and/or regional priorities;

e) has standards for the commissioning of services which are readily understood and are available to the public; and

f) ensures that service users have access to its services within locally and/or regionally agreed timescales.

6.3.2 Service Delivery for Individuals, Carers and Relatives

The organisation:

a) ensures that all service users, carers and relatives are treated with dignity and respect and that their privacy is protected and promoted, including, where appropriate, the use of advocates and facilitators;

b) has systems in place to ensure that service users, carers and relatives have the appropriate information to enable them to make informed decisions and choices about their treatment and care, or service provision;

c) ensures that information, where appropriate, is provided in a number of formats, which may include, large print, audio format on tape or compact disc, computer readable format, Braille, etc. and is:

- written in easy to understand, non-technical language;
- laid out simply and clearly;
- reproduced in a clear typeface;
- available on the internet; and
- in the preferred language of the reader, as necessary;

d) incorporates the rights, views and choice of the individual service user into the assessment, planning, delivery and review of his or her treatment and care, and recognises the service user’s right to take risks while ensuring that steps are taken to assist them to identify and manage potential risks to themselves and to others;

e) ensures that individual service user information is used for the purpose for which it was collected, and that such information is treated confidentially;

f) promotes multi-disciplinary team work and integrated assessment processes, which minimise the need for service users and carers to repeat basic information to a range of staff; and

g) provides the opportunity for service users and carers to provide comment on service delivery.

Section 7: Promoting, Protecting and Improving Health and Social Well-being (Theme 4)

7.1 Standard Statement

The HPSS works in partnership with service users and carers, the wider public and with local and regional organisations to promote, protect and improve health and social well-being, and to tackle inequalities within and between geographic areas, socio-economic and minority groups, taking account of equality and human rights legislation.

7.2 Rationale

Individuals, families and carers have a major part to play in their own and their dependents' health and social well-being. Although many factors influence the health and social well-being of individuals, many of these factors are societal issues and are outside the control of individuals. Examples include poverty, social exclusion, poor education, unemployment, crime, and poor housing. Resolving these issues requires a broad-based approach and concerted action by a wide range of people and agencies including the statutory, voluntary, community and business sectors. The HPSS, working in partnership with these other agencies and community groups, should actively seek to influence and support better decision-making, and establish systems to promote and improve the health and social well-being of the public and to reduce inequalities. The goal is to improve the health and social well-being of the population of Northern Ireland, by increasing the length of their lives, improving the quality of life through increasing the number of years spent free from disease, illness, or disability, and by providing better opportunities for children and support for families.

7.3 Criteria

The organisation:

a) has structures and processes in place to promote and implement effective partnership arrangements, to contribute to improvements in health and social well-being, and promote social inclusion and a reduction in inequalities;

b) actively involves the services users and carers, the wider public, HPSS staff and the community and voluntary sectors, in the planning and development of local solutions to improve health and social well-being and to reduce inequalities;

c) is committed to human rights, as identified in human rights legislation and United Nations Conventions, and to other Government policies aimed at tackling poverty, social need and the promotion of social inclusion;

d) actively pursues equality screening and, where appropriate, equality impact assessment in compliance with section 75 of the Northern Ireland Act 1998;

e) promotes ownership by service users, carers and communities to enable service users and the public to take responsibility for their own health, care and social well-being, and to participate as concerned citizens in promoting the health and social well-being of others;

f) collects, collates, develops and uses health and social care information to assess current and future needs of local populations, taking account of health and social well-being inequalities;

g) has effective and efficient emergency planning processes and co-ordinated response action plans in place, as appropriate, to deal with major incidents or emergency situations and their aftermath. The planning processes and action plans are compliant with Departmental guidance;

h) has processes to engage with other organisations to reduce local environmental health hazards, as appropriate;

i) has evidence-based chronic disease management programmes and health promotion programmes and, as appropriate, community development programmes, which take account of local and regional priorities and objectives;

j) has systems to promote a healthier, safer, and "family friendly" workforce by providing advice, training, support and, as appropriate, services to support staff;

k) has quality assured screening and immunisation programmes in place, as appropriate, and promotes active uptake among service users, carers and the public;

l) uses annual public health and social care reports in the development of priorities and planning the provision and delivery of services; and

m) provides opportunities for the use of volunteers, as appropriate.

Section 8: Effective Communication and Information (Theme 5)

8.1 Standard Statement

The HPSS communicates and manages information effectively, to meet the needs of the public, service users and carers, the organisation and its staff, partner organisations and other agencies.

8.2 Rationale

Good communication and effective use of information are the basis for decision-making by individuals, the public and organisations. They ensure that all relevant facts are collated and used to inform treatment and care, and the assessment, planning, service delivery and resource allocation processes. For information to be useful, it needs to be in an understandable format, accessible to those who need it and readily available. The communication and information management processes within an organisation must take account of the needs of service users and carers, staff and the public and the media, and any legislative or regulatory requirements. Protecting personal information and confidentiality are important to ensure that information is appropriately communicated to those who need to know and effectively used to inform any decisions made. The HPSS should be sensitive to the range of information needs required to support individuals, communities and the organisation itself.

8.3 Criteria

The organisation has:

a) active participation of service users and carers and the wider public. This includes feedback mechanisms appropriate to the needs of individual service users and the public;

b) an effective information strategy and communication strategy, appropriate to the needs of the public, service users and carers, staff and the size, functions and complexity of the organisation;

c) an effective and integrated information technology and information systems which support and enhance the quality and safety of care and provision of services;

d) system(s) and process(es) in place to ensure that urgent communications, safety alerts and notices, standards and good practice guidance are made available in a timely manner to relevant staff and partner organisations; these are monitored to ensure effectiveness;

e) clear communication principles for staff and service users, which include:

- openness and honesty;
- use of appropriate language and diversity in methods of communication;
- sensitivity and understanding;
- effective listening; and
- provision of feedback.

f) clear information principles for staff and service users, which include:

- person-centred information;
- integration of systems;
- delivery of management information from operational systems;
- security and confidentiality of information; and
- sharing of information across the HPSS, as appropriate;

g) the organisation has effective training for staff on how to communicate with service users and carers and, where needed, the public and the media;

h) effective records management policies and procedures covering access and the completion, use, storage, retrieval and safe disposal of records, which it monitors to assure compliance and takes account of Freedom of Information legislation;

i) procedures for protection of service user and carer information which include the timely sharing of information with other professionals, teams and partner organisations as appropriate, to ensure safe and effective provision of care, treatment and services, e.g. in relation to the protection of children or vulnerable adults, and the safe and efficient discharge of individuals from hospital care;

j) effective and efficient procedures for obtaining valid consent for examination, treatment and/or care;

k) an effective complaints and representation procedure and feedback arrangements, which is made available to service users, carers and staff and which is used to inform and improve care, treatment and service delivery; and

l) a range of published up-to-date information about services, conditions, treatment, care and support options available, and how to access them both in and out of service hours, which are subject to regular audit and review.

APPENDIX 1

GLOSSARY OF TERMS

Adverse incident	Any event or circumstance that could have or did lead to harm, loss or damage to people, property, environment or reputation.
Carer	Carers are people who, without payment, provide help and support to a family member or friend who may not be able to manage at home without this help because of frailty, illness or disability.
Care plan	The outcome of an assessment. A description of what an individual needs and how these needs will be met.
Care Standards	Care Standards are service specific standards currently being developed. They will cover a range of services provided by public, voluntary and private organisations such as nursing homes, residential homes, independent clinics etc.
Clinical and Social Care Governance	A framework within which HPSS is accountable for continuously improving the quality of their services and safeguarding high standards of care and treatment.
Community care	Health and social services aimed at supporting individuals to remain safely in their own homes for as long as possible.
Community development	Consultation with, and involvement of local communities and groups in improving health and social well-being of the community.
Controls Assurance Standards	These standards focus on key areas of potential risk and help HPSS organisations demonstrate that they are doing their reasonable best to manage themselves and protect stakeholders from risk. They support effective governance.
Equality impact assessment	Consideration of a policy having regard to its impact on and the need to promote equality of opportunity between: persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation, men and women generally, persons with a disability and persons without and between persons with dependants and persons without.
Evidence based practice	Provision of services which are based on best practice as proven by research findings, scientific knowledge and evaluation of experience.
Family Practitioner Services (FPS)	The principal primary care services i.e. family doctors, opticians, dentists and pharmacists.
HPSS (Health and Personal Social Services)	An organisation which either commissions or provides health and social services, e.g. HSS Boards, Strategic Health and Social Care Authority, a Trust providing hospital and community services, a local commissioning body, and Family Practitioner Services.

NPSA	The National Patient Safety Agency promotes safe practice in clinical care and supports the development of solutions and the cascade of learning to reduce areas of high risk.
Person-centred assessment	An assessment, which places the individual at the centre of the process and which responds flexibly and sensitively to his/her needs.
Primary care	The many forms of health and social care and/or treatment accessed through a first point of contact provided outside hospitals e.g. family doctors, pharmacists, nurses, allied health professionals (physiotherapists, psychologists, dieticians etc) social workers, care assistants, dentists, opticians and so on.
Secondary care	Specialist services usually provided in an acute hospital setting following referral from a primary or community healthcare professional.
Statutory duty	A legal responsibility.
Statutory sector	Government-funded organisations e.g. HSS Boards, Strategic Health and Social Services Authority, Trusts, Special Agencies and Local Commissioning Groups.
Tertiary care	Highly specialised services usually provided in an acute hospital setting by medical and other staff with expertise in a particular medical specialty.

APPENDIX 2

REFERENCES, CIRCULARS AND PUBLICATIONS

Legislation

1. Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003.

Circulars

2. Circular HSS (OS) 1/73 – (DHSSPS) Notification of untoward events in psychiatric and special hospitals.

3. Circular HSS (PDD) 1/1994 – (DHSSPS) Management of Food Services and Food Hygiene in the HPSS.

4. Circular HSS (THRD) 1/97 – (DHSSPS) Notification of untoward events in psychiatric and specialist hospitals for people with learning disability.

5. Circular HSS (THR) 1/1999 – (DHSSPS) Management of Food Services and Food Hygiene in the HPSS.

6. Circular HSS (PPM) 3/2002 - Corporate Governance: Statement on Internal Control (DHSSPS) http://www.dhsspsni.gov.uk/hss/governance/guidance.asp.

7. Circular HSS (PPM) 6/2002 – AS/NZS 4360: 1999 – Risk Management (DHSSPS) http://www.dhsspsni.gov.uk/hss/governance/guidance.asp.

8. Circular HSS (PPM) 8/2002 – Risk Management in the Health and Personal Social Services (DHSSPS) http://www.dhsspsni.gov.uk/hss/governance/guidance.asp.

9. Circular HSS (PPM) 10/2002 – Governance in the HPSS: Clinical and Social Care Governance - Guidance on Implementation (DHSSPS) http://www.dhsspsni.gov.uk/hss/governance/guidance.asp.

10. Circular HSS (PPM) 13/2002 – Governance in the HPSS – Risk Management (DHSSPS) http://www.dhsspsni.gov.uk/hss/governance/guidance.asp.

11. Role and Responsibilities of Directors for the Care and Protection of Children (Circular CC3/02), (DHSSPS), June 2002.

12. Circular HSS (F) 20/2002 – Clinical Negligence: Prevention of Claims and Claims Handling (DHSSPS).

13. Circular HSS (MD) 39/02 – (DHSSPS) Safe administration of Intrathecal Chemotherapy.

14. Circular HSS (PPM) 5/2003 – Governance in the HPSS: Risk Management and Controls Assurance (DHSSPS)
http://www.dhsspsni.gov.uk/hss/governance/guidance.asp

15. HSS (MD) 7/2003 A Reference Guide to Consent for Examination, Treatment or Care; and Good Practice in Consent, Consent for Examination Treatment or Care: A Handbook for the HPSS
www.dhsspsni.gov.uk/phealth/urgent_letter.asp.

16. HSS (MD) 36/03 Transmissible Spongiform Encephalopathy agents: safe working and the prevention of infection: publication of revised guidance
www.dhsspsni.gov.uk/phealth/urgent_letter.asp.

17. HSS (MD) 45/03 Updated National Guidance of the Safe Administration of Intrathecal Chemotherapy.

18. Circular HSS (PPM) 6/2004 – Reporting and follow-up on serious adverse incidents: Interim Guidance (DHSSPS)
http://www.dhsspsni.gov.uk/hss/governance/guidance.asp.

19. Circular HSS (PPM) 8/2004 – Governance in the HPSS: Controls assurance standards – update
http://www.dhsspsni.gov.uk/hss/governance/guidance.asp.

20. Circular HSS (F) 2/2004 - Statement on Internal Control – Full Implementation for 2003/04 (DHSSPS)
http://www.dhsspsni.gov.uk/hss/governance/guidance.asp.

21. HSS (MD) 08/04 Protecting the blood supply from variant CJD-deferral of donors who have received a blood transfusion
www.dhsspsni.gov.uk/phealth/urgent_letter.asp.

22. HSS (MD) 10/2004 Good Practice in Consent, Regional forms and Guides
www.dhsspsni.gov.uk/phealth/urgent_letter.asp.

23. HSS (MD) 17/04 Reducing the risk of exposure to the agent of CJD through brain biopsies www.dhsspsni.gov.uk/phealth/urgent_letter.asp.

24. HSS(MD) 20/04 and 21/04 (DHSSPS) Decontamination of endoscopes
www.dhsspsni.gov.uk/phealth/urgent_letter.asp.

25. HSS (MD) 23/04 influenza and pneumococcal programme for 2004/2005 www.dhsspsni.gov.uk/phealth/urgent_letter.asp.

26. HSS (MD) 24/04 Childhood immunisation programme. www.dhsspsni.gov.uk/phealth/urgent_letter.asp.

27. Circular HSS (PPM) 5/05 Reporting of Serious Adverse Incidents within the HPSS. http://www.dhsspsni.gov.uk/publications/2005/hssppm05-05.doc

28. NIAIC Safety Notice MDEA (NI) 2006/01 Reporting Adverse Incidents and Disseminating Medical Device / Equipment Alerts. Health Estates, Northern Ireland Adverse Incident Centre.

Standards

29. Quality Living Standards for Services: Children Living in a Family Placement (DHSSPS), 1995.

30. Quality Living Standards for Services: Children who live away from Home (DHSSPS), 1995.

31. Quality Standards – Assessment and Care Management, (DHSSPS) 1999.

32. Quality Standards – Consumer Involvement in Community Care Services, (DHSSPS) 1999.

33. Partnership in Caring – Standards for Services, (DHSSPS) April 2000.

34. Standards for Social Work Services for Young Disabled Adults, January 2003.

35. Draft Standards for Disabled Children in Hospital, DHSSPS, January 2003.

36. Draft Standards for Child Protection, (DHSSPS), September 2003.

37. Approved Social Work in Northern Ireland: From Recommendations to Standards, (DHSSPS), June 2004.

38. Inspection of Social Care Support Services for Carers of Older People – Consultation on Draft Standards, July 2004.

39. Draft Standards: Approved Social Workers, (DHSSPS), November 2004.

40. A Statement of Healthcare Standards – Standards for NHS bodies in Wales, (Welsh Assembly) 2004.

41. National Standards – Local Action Health and Social Care Standards and Planning Framework 2005/6-2007/8 (Department of Health), 2004.

42. Standards for Better Health – Health Care Standards for Services under the NHS- (Consultation Document), Department of Health, 2004.

43. Summary of Responses to Standards for Better Health (Department of Health), 2004.

44. Care Standards for Northern Ireland (draft), (DHSSPS) 2004-05, standards available on www.dhsspsni.gov.uk/hss/care_standards/index.asp.

45. Controls Assurance Standards (DHSSPS), current standards available on http://www.dhsspsni.gov.uk/hss/governance/guidance.asp.

46. From Dependence to Independence – Standards for Social Work Services for Young Disabled Adults, Key Standards and Criteria, (DHSSPS).

47. Clinical Governance & Risk Management: Achieving safe, effective, patient-focused care and services – National Standards (NHS QIS, October 2005)

Guidance

48. Guidance on Implementation of the HPSS Complaints Procedure, (DHSSPS), March 1996 **(The HPSS Complaints Procedure is currently under review and will be replaced with effect from 2006)**.

49. Code of Practice on the Recruitment, Assessment, Approval, Training, Management and Support of Foster Carers, (DHSSPS) June 1999.

50. Guidance on Good Clinical Practice and Clinical Trials (1999), Department of Health, London.

51. Guidance on Handling HPSS Complaints: Hospital, Community Health and Social Services, (DHSSPS) April 2000 **(The HPSS Complaints Procedure is currently under review and will be replaced with effect from 2006)**.

52. Guidance for reporting accidents with, and defects in, medicinal products (2001), DHSSPS.

53. Guidance to Trusts on reporting defective medicinal products (2001), DHSSPS.

54. Guidance on the Management of HIV Infected Health Care Workers and Patient Notification (DHSSPS), July 2002.

55. A guide to pharmaceutical clinical waster (DHSSPS) (2002).

56. Safety Alerts (NIAIC, Health Estates Agency, Northern Ireland) on www.dhsspsni.gov.uk/safety.asp-2003.

57. Guidance Note - Implementing the Equality Good Practice Reviews (DHSSPS) 2004 http://www.dhsspsni.gov.uk/econsultation/Good_practice/GPRs_circ_HSSPS29Jan04.pdf

58. 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’, (DHSSPS), October 2004.

59. Guidance on ‘Drug and Substance Misuse in Mental Healthcare Settings’, (DHSSPS), October 2004.

60. Use and Control of Medicines: Guidelines for the safe prescribing, administration, handling, storage and custody of medicinal products in the Health and Personal Social Services (2nd edn.2004), DHSSPS.

61. Drug alerts –issued by the Chief Pharmaceutical Officer on www.dhsspsni.gov.uk/pgroups/pharmaceutical/alerts.asp

Other National Publications

62. Department of Health 2000, *an Organisation with a Memory. Report of an Expert Group on Learning from Adverse Events in the NHS*. The Stationery Office, London.

63. Lessons for CHI Investigations 2000-2003. Commission for Health Improvement.

64. A.M.Beaney (ed) (2001) Quality Assurance of Aseptic Preparation Services (3rd Edition) Pharmaceutical Press, London.

65. Department of Health 2001, Clinical Governance in Community Pharmacy. Guidelines on good practice for the NHS. Department of Health, London.

66. Department of Health 2001, Building a Safer NHS for Patients. Implementing an Organisation with a Memory, Department of Health, London.

67. Doing Less Harm; Improving the Safety and Quality of Care through Reporting, Analysing and Learning from adverse incidents, Department of Health and NPSA August 2001.

68. Quality Assurance of Radio Pharmaceuticals: The Radiopharmacy Group and the NHS Pharmaceutical Quality Control Committee. Nuclear Medicine Communications 2001; 22:909-916.

69. Vincent C, (ed) Clinical Risk. London: BMJ Publishing (2001).

70. Crossing the Quality Chasm: A new Health System for the 21st Century. National Academy of Sciences, 2003 www.nap.edu/catalog/10027.html.

71. Development of Integrated Governance, NHS Confederation, 2004.

72. Sharing the Learning on Patient and Public Involvement from CHI's Work. Commission for Health Improvement www.chi.nhs.uk.

73. Social Care Institute for Excellence (SCIE): Knowledge Review 7: Improving the use of research in social care practice http://www.scie.org.uk/.

74. SCIE: Practice guide on managing practice. http://www.scie.org.uk/.

75. SCIE: Report 4: Using systematic reviews to improve social care. http://www.scie.org.uk/.

76. SCIE: Report 5: User participation in the governance and operations of social care regulatory bodies. http://www.scie.org.uk/.

77. SCIE: Report 6: Managing risk and minimising mistakes in services to children and families. http://www.scie.org.uk/.

78. SCIE: Research Briefing 1/01: Preventing falls in care homes. http://www.scie.org.uk/.

79. SCIE: Research Briefing 1/15: Helping older people to take prescribed medication in their own homes: what works. http://www.scie.org.uk/.

80. SCIE: Resource Guide 3: Teaching and learning communication skills in social work education. http://www.scie.org.uk/.

81. SCIE: Resource Guide 05: Direct Payments: answering frequently asked questions. http://www.scie.org.uk/.

82. The Patient Safety Observatory Report – Building a Memory: Preventing Harm, Reducing Risks and Improving Patient Safety (NPSA, July 2005).

Other Local Publications

83. From Hospital to Home, (DHSSPS) 1997.

84. Children's Service Planning Guidance, (DHSSPS) July 1998.

85. Building the Way Forward in Primary Care (DHSSPS) Dec 2000.

86. Best Practice – Best Care (2001) – A framework for setting standards, delivering services and improving monitoring and regulation in the HPSS (DHSSPS) http://www.dhsspsni.gov.uk/publications/archived/2001/4161finaldoc.asp

87. Building the Community Pharmacy Partnership (DHSSPS), April 2002

88. Best Practice Best Care - Summary of Responses to the Consultation (DHSSPS), May 2002.

89. Protecting Personal Information in the HPSS (DHSSPS), July 2002.

90. Northern Ireland Social Care Council: Codes of Practice for Social Care Workers and Employers of Social Care Workers, September 2002 http://www.niscc.info/.

91. Mental Health Social Work (DHSSPS), April 2003.

92. Social Work Services for Adults with Sensory Impairment, (DHSSPS) July 2003.

93. Tackling Violence At Home, (DHSSPS), October 2003.

94. Evaluation of HPSS Baseline Assessment and Action Plan – Clinical and Social Care Governance (Deloitte Touche, on behalf of DHSSPS), 2003.

95. Good Management, Good Records, (DHSSPS), December 2004.

96. A Healthier future- A Twenty Year Vision for Health and Wellbeing in Northern Ireland (DHSSPS) 2004.

97. The Review of the Public Health Function in Northern Ireland- consultation document (DHSSPS) 2004.

98. Public Attitudes Survey (2004), Research Evaluation Services.

99. Priorities for Action for the Health and Personal Social Services (DHSSPS) 2004-05 http://www.dhsspsni.gov.uk/prior_action/index.asp.

100. SARS information and plans (DHSSPS) www.sarsni.gov.uk, SARS (urgent communications) available on www.dhsspsni.gov.uk/phealth/urgent_letter.asp.

101. 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) http://www.dhsspsni.gov.uk/publications/2005/primary-care.pdf

102. A Healthier Future: A Twenty Year Vision for Health and Wellbeing in Northern Ireland 2005-2025 (DHSSPS, 2005) http://www.dhsspsni.gov.uk/publications/2004/healthyfuture-main.pdf

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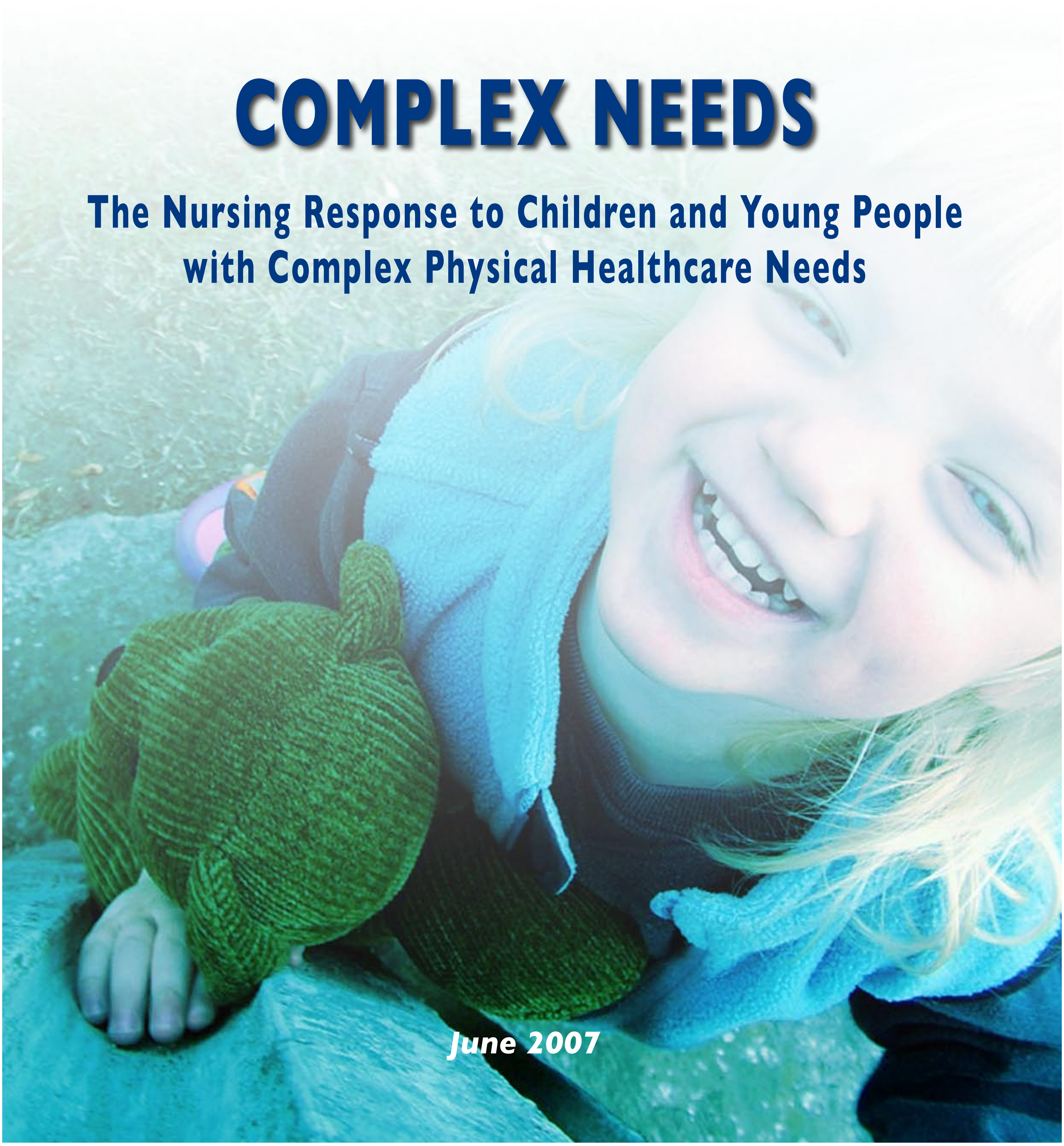

COMPLEX NEEDS

The Nursing Response to Children and Young People with Complex Physical Healthcare Needs

June 2007

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Institute of Nursing Research

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Executive Summary

The aim of this project, as set by DHSSPS, was to undertake a review of nursing services in order to ensure that they are facilitated to fully support and respond to children with complex needs and their families, and for them to work in partnership with other professions and agencies. However this review needed to take into account the wider service context and commissioning frameworks.

The project commenced in November 2006. In addition to reviewing the international literature, information was gathered from 30 parents, nearly 200 frontline professionals and 30 service managers. Throughout the project, participants repeatedly demonstrated an interest and enthusiasm to produce more efficient and effective service responses to an estimated 500 children and families in Northern Ireland which to date has been ad hoc and often uncoordinated. Many inequities exist in provision across Northern Ireland. Yet individual packages can be a high expense to HPSS.

A series of recommendations have been developed which command a consensus among informants. Chief among them are:

- The need for a specific service framework to guide the commissioning and delivery of services to this client group.
- The development of an assessment instrument for common use throughout Northern Ireland to assist in determining service needs.
- A focus on individualised, family-centred planning and delivery of support services, and improved co-ordination arrangements among them.
- The need for assured funding for community children's nursing services and the provision of flexible 'out-of-hours' responses by nurses in the community.
- Greater interchange between children's nursing in acute and community settings; and an audit of community nursing services.
- Joint planning of provision with the Department of Education; notably on the development of joint funding arrangements and having common healthcare assistant posts.
- Regional training initiatives for nurses and healthcare assistants in the care of the children and their families.
- Improved transition planning, notably from acute hospitals to community; school entry, school transfer and school leaving.
- Review by DHSSPS of the provision of equipment.
- Review by DHSSPS and the Health & Social Care Authority of respite arrangements for these children and families and an increase in the availability of appropriate respite options.

The importance is stressed of continuing the momentum generated by the Project. An action plan for taking forward the work is proposed. For too long this issue has drifted to the detriment of parental and practitioner morale. A common consensus and will for action exists.

Further work is required around palliative care services for children and 'end-of-life' issues along with appropriate service provision to these families when the children become adults.

Section 1: Introduction to the Project

At the outset, we would like to pay tribute to the parents and professionals involved with this group of children. They truly have gone the extra mile in providing the children with loving homes, exemplary care and a dedication that has overcome many obstacles and disappointments in what is an evolving area of community health services.

Much of what is written in this report is critical – hopefully constructively so - of our current systems and the way support services have been provided to these children. This has forced people to act in ways that are not always productive or efficient. New wine has been poured into old bottles. Our hope is that we can learn from all these experiences so that more suitable service responses are shaped for the new wine that we as a caring society need to nurture and mature.

Terms of reference

The aim of this project as set by DHSSPS was to ensure that nursing services are facilitated to fully support and respond to children with complex needs and their families in partnership with other professions and agencies. This includes Community Children's Nurses (CCNs), Community Learning Disability Nurses (CLDNs) and School Nurses as well as those working with children in acute hospitals. These nursing services should significantly contribute to quality of life ensuring that children, young people and their families are enabled to experience a life that is as full and as normal as possible.

In particular the project should identify:

- Model(s) of service delivery for Northern Ireland
- Systems which are required to support the delivery of recommended models of service.
- Elements of systems in which nursing has a particular responsibility to take the lead in securing effective development, delivery and review of services.
- Workforce requirements, training and development needs; funding arrangements and outcome/performance measures.

Although the aims were specific to nursing, these had to be set within a broader service context. This included community health and social services, acute hospital services as well as educational and voluntary sector provision. Indeed the complexity of service responses is another reflection of the challenges these children and families propose to our existing provision.

Policy and Legislative Context

The policy and legislative context for service provision has been well summarised in a variety reports and policy documents. Moreover legislation is in place that covers this group of children. As will become apparent throughout this report, there is a consensus on what needs to be done. It is the implementation of the necessary actions is often lacking.

For *all* children

Government has moral and legal obligations and responsibilities to identify and address the needs of these children and their parents. These are contained in:

- The principles set out in the UN Convention on the Rights of the Child 1989 (www.unhchr.ch/html/menu3/b/k2crc.htm) provide the broad principles that underpin the way in which services develop and progress.

- The aim of the 10 year Strategy for Children and Young People in Northern Ireland (www.allchildrenni.gov.uk) is to ensure all children and young people in Northern Ireland are fulfilling their potential and indeed emphasises that actions must be taken to improve the lives of those children, young people and their families who need help most. It recognises that the link to the respect for rights is central to the successful delivery of the outcomes framework described in the Strategy.
- The emphasis on rights is reiterated in the Green Paper, *Every Child Matters,* 2003 (www.everychildmatters.gov.uk/publications) which also recognises the deficits within service systems and the need to protect children through early intervention, sharing of information, effective co-ordination of services and appropriate training of staff.

Nationally and internationally a series of governmental and professional reports have delineated the role and nature of service provision that is required. For over 40 years now, it has been well recognised that children are best cared for at home (Platt Report, 1959) and with the increasing numbers of children surviving due to advances in medical technology, there is an ever increasing emphasis on Community Children's Nursing teams with the skills and competencies to provide specialist care within the home setting (House of Commons Select Committee (1997); Health Services for Children and Young People in the Community: Home and School, Third Report, available from www.publications.parliament.uk).

Multi-disciplinary working is seen as instrumental in the smooth transition of a child with complex needs from hospital to their home environment and the need for a seamless approach is emphasised in Department of Health (1996) *Child Health in the Community: A Guide to good practice* www.dh.gov.uk/assetRoot/04/01/24/50/04012450.pdf. This was further emphasised by the Audit Commission's Review (2003) of *Services for disabled children*.

The National Service Framework for Children and Young People and Maternity Services 2004 www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices emphasises the need to provide appropriate support to children and young people and their families at a local level. It also addresses the provision of care for children with complex needs as well as setting standards regarding the delivery of care.

Likewise the DHSSPS (2004) *A Healthier Future, a 20 year Strategy;* DHSSPS (2005) *Primary Care Strategy Framework for Caring for People beyond Tomorrow* and DHSSPS (2000) *Partnerships in Caring* all contain recommendations to develop a model of service which supports the child and family in the home while ensuring links are developed into secondary and tertiary care when required.

For children with complex needs

There is an ever increasing commitment to service development for children with complex needs; for example, as reflected in the publications available from the RCN (2003) *Community Children's Nursing Effective Team Working*: www.rcn.org.uk.

Within Northern Ireland, a series of pertinent reports have been produced by DHSSPS including *Nursing Services for the acutely ill child in Northern Ireland (1999)*: www.dhsspsni.gov.uk/726_nursing_services.pdf.

The need for discharge planning was also a key aspect of *Care at its Best: the Regional Multidisciplinary Inspection of the Services for Disabled Children in Hospital* (2005) www.dhsspsni.gov.uk/care-main-report.pdf as was the lack of provision of respite for children, young people and their families which is a key element when supporting families.

The DHSSPS consultative document: *Strategy for Children in Need* (2003) explored the impact of multi-agency and multidisciplinary working on children with complex needs and their families and urged a coherent approach to service provision. Emphasis was placed on the need to work in partnership, have a shared vision and the need for a key worker.

The *Equal Lives Report* (2005) of the Bamford Review on Mental Health and Learning Disability recommended an extension in the volume and range of emotional and practical help that is available to support families and urged the establish of multi-agency centres to provide a clear pathway to services for parents and carers.

In support of parents

In January 2007, the Family Policy Unit of DHSSPS produced for consultation, proposals for a Regional Family and Parenting Strategy (www.dhsspsni.gov.uk/families-matter-consultation-document.pdf) under the title ‘Families Matter’. Although the focus is primarily on prevention and early intervention, the Strategy recognises “the importance of valuing parents and not diminishing their role and responsibility. Seeking help does not mean that parents simply want to hand over control of their children to others” (p.7).

Legislation

A range of legislation places duties and responsibilities on health, social service and education in relation to the children and young people but also to family carers. This includes:

Education (NI) Order (1996).

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. Although the statement may specify particular health services, these remain the responsibility of HSS Trusts to provide.

The Children Order (N.I.) (1995)

This Order brings together most public and private law relating to children and established a new approach to services provided by Health and Social Services Trusts for children and their families. It 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).

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.

Disability Discrimination Act (1996) and SENDO (2006)

This Act aims to ensure that disabled people have equal opportunities in terms of access to employment, buildings, and goods and services. The Special Educational Needs and Disability Order (SENDO) requires schools, colleges and universities to provide information for people with disabilities and make suitable accommodation for their needs.

Legislation relating to carers

In the UK, there have been four Acts of Parliament specifically for carers:

- The *Carers (Recognition and Services) Act 1995*. This gave carers the right to an assessment of their own needs in Great Britain ands was recommended as good practice by Health and Social Service Trusts in Northern Ireland.
- *The Carers and Disabled Children Act 2000.* This extended the right to assessment for adults and the provision of services to carers. It also extended the rights to 16 and 17 year old young people who are carers as well as to parents of disabled children.
- *The Carers and Direct Payments (Northern Ireland) Act 2002* places a duty also on HSS Trusts to inform carers of their right to an assessment and to undertake these.
- *The Carers (Equal Opportunities) Act 2004*. This new Act places a duty on local authorities to tell carers about their rights and places a duty on them to consider whether the carer works or wishes to work, wishes to study or have some leisure activities, when they are carrying out a carer's assessment gives local authorities strong powers to enlist the help of health, housing and education authorities in providing support for carers. However this Act has yet to be implemented in Northern Ireland.

In conclusion, no new legislation or policy statements are required. Rather the project had to identify the action steps that need to be taken in order to fulfil the intentions contained in legislation and the numerous policies initiatives of recent years as detailed above.

Values underpinning service provision

Recent legislation and policy statements reflect a new set of child and family-centred values and principles. These derive from increases in knowledge as well as changes in societal attitudes and aspirations. Thus at the outset, it was important to specify the values and principles that should guide the service provision for children with complex physical healthcare needs and for their families. This is all the more necessary as these children form a new service group that has emerged due to the medical and nursing advances that have sustained and prolonged their lives.

Table 1: Six key values to underpin services

- Children are best cared for at home and within families;
- The ordinary needs of children and families have to be met as well as their special needs;
- Parents know their child better than anyone else and must be treated respectfully by professionals as equal partners given the expertise they have in the care of their child;
- Professional supports must be co-ordinated and responsive to the needs of individual children and families.
- Risks to the child’s life need to be managed in ways that provide safety and a good quality of life to the child and family;
- Partnership working across disciplines and agencies is essential.

Throughout the project a number of key values were re-iterated by parents and professionals. They are explicitly stated in Table 1 so that common ownership is established across commissioners and providers; by parents and professionals. They also echo the Standard set in the National Service Framework for disabled children and young people with complex health needs (Department of Health, 2004); see Appendix 2a.

Summary of the process

Figure 1 summarises the process followed in the Project. The aim was to have a process that was inclusive and participative.

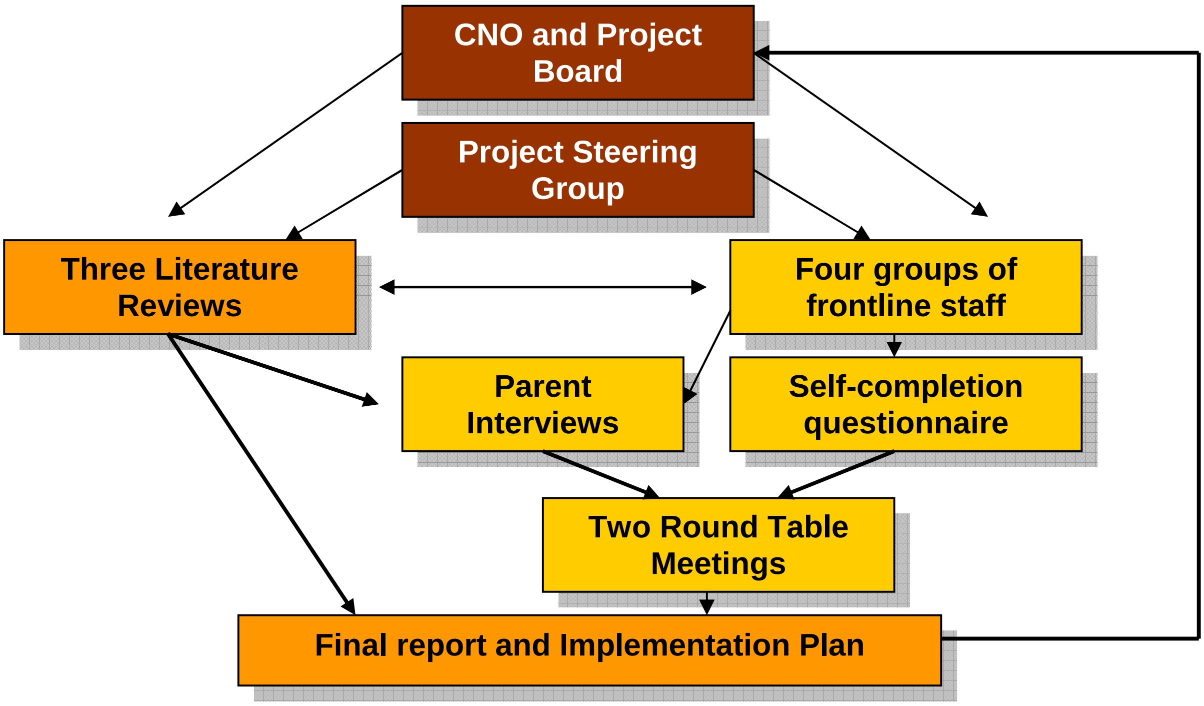

Figure 1: An overview of the process followed.

- It was **inclusive** of parents, front-line support staff, service managers and commissioners as well as those working in community health, social services, acute hospitals, education and the voluntary sector. However time and resources did not allow us to consult as fully with the children as we would have liked.
- **Participation** was achieved for parents through interviews and for professionals by group meetings and self-completion questionnaires. An iterative process was used of feeding back findings as they were obtained.

It was an **efficient** process. A time line was set and maintained over the four-month period. The University team had dedicated time to facilitate the process and the necessary skills and experience to synthesise and analyse the information gained.

The process also aimed to bring together in an **integrated** way, the experiences and insights of all the major service systems involved with this issue: Departments and HSS Boards; HSS Trusts; Education and Library Boards and the voluntary sector. Previously issues relating to this group of children had been debated mostly within single systems.

Throughout the expertise and experience of parents and the workforce was used as the primary knowledge base for system failings and improvements. We trusted people's assessments and judgements. However we were able to cross-check and validate their views by collecting information from different groups and using different methods for gathering the information. We were impressed by the willingness of informants to engage with us. Often the numbers contributing were double what we expected or hoped to achieve. This is perhaps an indication of the concern which participants had of the need for action.

Other options for information gathering were considered but were not included in our tender, such as service activity analyses or file searching. We gauged that the effort spent on these ‘fact-finding’ methods would not yield the information required in the time available.

Project Board and Project Steering Group

Two groups were established to oversee and guide the work of the Project. Their terms of reference and membership are given in the Appendix. The Board focussed more on policy and strategic issues with particular reference to inter-agency working while the Steering Group dealt more with operational and practice issues. Educational personnel as well as parents were represented on both groups and made a valuable contribution.

Each group met on five occasions in the period November 2006 - March 2007. The groups were crucial in assisting with access to service personnel and then to families. They contributed greatly to identifying core issues and helped in framing the final report and implementation plan.

Audit of service provision

The information gathered by the Project was considered as an audit of provision rather than as research. This was confirmed by the Office for Research Ethics in Northern Ireland (OREC-NI). Hence formal ethical approval was not sought for the information gathering.

Nonetheless informed consent was obtained from all individual participants in the project. This stressed the confidentiality of the information provided and the option not to answer any questions and to discontinue participation without giving a reason.

Consent forms were signed by participants in interviews and focus groups. The completion of the postal questionnaire was seen as implicit consent.

The remainder of the report is framed around each element of the process in Figure 1. The Appendices to the Report give fuller details of each aspect of the Project’s work.

Section 2: Lessons from the Literature

The Project Team undertook reviews of the literature around three themes that were pertinent to the Project.

1. The needs of children and families
2. Multi-agency and multi-disciplinary working
3. Community nursing services to children

The literature consisted mainly of articles in international journal, supplemented by book chapters or reports. The priority was to identify the implications for services within Northern Ireland from experiences elsewhere. The reviews were written with a service readership in mind. The reviews are given in Appendix 2 with the key messages from each summarised below.

1. The needs of children and families.

The key message is that the needs of children must be seen within an empowered family context.

The impact of having a child with complex physical health needs in the family is a combination of positive and negative consequences: a combination of joy (at achievements however limited) and sorrow (from missed opportunities and distress experienced). Many parents and siblings demonstrate tremendous resilience and develop a range of effective coping strategies which helps them to respond to the challenges they encounter.

The impact on the family spans physical, psychological and social domains, and therefore to be effective, interventions by professionals must do the same. However their interventions must empower parents so that they remain in control of their life and that of their child. In seeking to support families it is important to respond to the key areas of parental need that have been identified within the literature review, namely:

- The need for increased certainty;
- The need for information;
- The need to acquire knowledge and develop skills in caring for their child;
- The need for co-ordinated services;
- The need for respite care.

In developing future services whose hallmarks are engagement and partnership, it is also necessary to bear in mind the characteristics that distinguish successful services for children with disabilities.

- Listening to disabled children and young people; listening to parents and other relevant family members;
- Providing information and advice and assisting parents to make use of it;
- Inculcating positive attitudes and a co-ordinated approach;
- Providing flexible support services which hare tailored to individual children’s and families needs

- Having more money so that financial pressures on children and parents are eased;
- Measuring the actions of all statutory and voluntary agencies against the human rights of disabled children

It is necessary to take time to obtain a clear understanding of how the child and all family members perceive their situation, and the coping strategies employed by individuals and the family as a functional unit. In doing so, a more accurate picture of family interactions and priorities is gained and consequently flexible support can be successfully targeted to facilitate family adaptation (Todd & Jones 2003, Hilbert et al 2000). Recognition of parental expertise is fostered by their participation in service planning, reviews and staff training.

2. Multi-agency and multi-disciplinary working

The key message is that effective co-ordination and information sharing is needed to make multi-agency working successful.

A dominant issue within health and social services at the start of the 21st century is the need for joint working with other departments and agencies in order to achieve better outcomes for service-users. The achievement of effective multi-agency working is a complex and intricate process which needs to be replicated at all levels within service systems – policy, operations and service-user. It is the latter aspect that currently holds most promise, namely making multi-agency working happen for individuals.

From the extensive literature that is now available on this theme, the following implications were drawn in determining a nursing response to families who have children with physical healthcare needs:

- Holistic support is required by families including their emotional and social needs. This is frequently neglected by professionals.
- Defined roles and structures need to be agreed for the team as a whole as well as for individual members of the team. This applies to different nurses who may be involved with the family. The leadership function must be clearly defined.
- A team development strategy is devised and the work of the team is regularly reviewed to assure a positive impact on children and families.
- A named person (key-worker/coordinator) should be appointed for each family.
- Trans-disciplinary practice should be encouraged across team members.
- Joint training opportunities should be provided across professions and parents.
- Nurse training should incorporate family-centred care and multi-disciplinary working.

Services need to focus on key themes such as ‘family support’ as they embody both the reasons for multi-disciplinary working and to ensure its delivery in a co-ordinated manner. Team members have an important advocacy role for families with their colleagues, managers and service commissioners.

A person-centred approach that is unique to each child and family is likely to provide the most efficient use of resources.

There are an increasing number of examples of delivering person-centred services; for example the Wraparound approach in the SHSSB (www.shssb.org/partnerships/wraparound/).

3. Review of community nursing services to children.

The key message is that community nursing services must continue to expand and develop in a creative, flexible and innovative way that characterises a pro-active service

Nine different models of nursing provision to children were identified and combinations of these can be seen around Northern Ireland. There is variation in current provision across HSS Boards and HSS Trusts than is not explained by different needs and demands for services.

Critical aspects in developing a community nursing service include:

- The physical and intellectual resources required to deliver innovative services to a high-risk group of children in potentially high-risk environments.
- Creating and developing a therapeutic culture that strives to meet the needs of children and families.
- Attention must be given to matters such as education and training, documentation, policy, funding, and professional development planning for lay and professional carers.
- Good practice, where it is identified must be exploited to effect better care for other families elsewhere in the region.
- Paying existing family carers, and the expansion of a variety of options of respite care in the home or another facility must be flexible and available, to lift the burden of caring and to attempt to normalize family life.
- Evaluation of services is an essential component especially in terms of securing future resources.
- Regional oversight of the development of children's nursing needs to be improved so that better workforce planning occurs to overcome the present shortage of paediatric trained nurses.

The outcome of initiatives to improve the quality of life and services to children with complex physical health needs will have implications for the development of all future services. It is therefore all the more important to design a nursing service that other areas might wish to follow. In addition nursing children with complex physical health needs in the community might offer lessons for other nursing disciplines facing parallel challenges, such as district nursing.

Conclusion

Internationally services are grappling with the many challenges that children with complex physical healthcare needs present to existing provision. There is no one answer or any speedy response. However the pool of expertise represented in the literature does identify the core issues that must be addressed and offers pointers in developing a strategy for service evolution. Nonetheless these have to be interpreted in the context of local circumstances. Hence a key aspect of the Project's work was an examination of the local situation in Northern Ireland.

Section 3: Definitions of complex physical healthcare needs

The project was focussed on children who had *physical* healthcare needs. It was recognised that complex health needs could include children and young people with behavioural difficulties, emotional problems or mental illnesses. Such children would also fall within this grouping provided they had a significant physical healthcare need as well. Otherwise children with behavioural and emotional problems were not included in this Project although it is likely that many of the recommendations contained in this report would be applicable to them.

Even so, the population of children and young people with physical healthcare needs are a heterogeneous group that are not easily defined in simple terms. They form a sub-set of children with disabilities and/or long-term illness but their defining characteristics are not easily identified. One approach is to base the definition around the child's characteristics, such as their medical condition. Hence the project began with this working definition:

> *"they are children primarily with physical care needs, such as those who are technologically dependent, have a life limited or life threatening condition, acquired brain injury resulting in significant impairment and /or children with multiple impairments from birth".*

An alternative approach was then considered. In the USA, the Federal Maternal and Child Health Bureau's Division of Services for Children with Special Health Care Needs (DSCSHCN) established a working group to develop a definition of children with 'special healthcare needs' (McPherson et al., 1998). Their recommended definition was:

> *"Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (p.138).*

The distinctive feature of this type of definition is that it defines a need for service which may not be determined solely by a child's condition. For example, two children may have an acquired brain injury but one may require additional services and another will not.

In Northern Ireland, The Children (NI) Order, 1995 placed a requirement on each HSS Trust to open and maintain within their geographical boundary a register of 'children with a disability'. The definition that was proposed by the Project Team who developed the business case for the Register (Association of Directors of Social Services, 2003) also reflected this focus on support:

> *"A child/young person has a disability if he/she has a significant impairment and, without the provision of additional assistance, resources or information, would be disadvantaged /restricted in, or prevented from, participating in the life of the community both in the manner which might reasonably be expected, and in comparison to other children of similar age, respecting individual culture and circumstances" (p.3)*

Following discussion with the Project Board and Steering group, we propose that a definition that focuses on support needs rather than children's conditions should be used.

Children (and young people) with complex physical healthcare needs are those who require a range of additional support services beyond the type and amount required by children generally and those usually provided to children with impairments and long-term illnesses.

The rationale is as follows:

- This approach is in keeping with the International Classification of Functioning promoted by the World Health Organisation (www3.who.int/icf/icftemplate.cfm).
- It is in line with social models of disability and illness that are widely accepted internationally.
- It links directly to person-centred (care) planning that attempts to address the individual needs of people rather than the provision of 'block treatments'.
- It is implicit within the development and operations of Service Frameworks and of individualised payments (Direct Payments).

However this type of definition is not easy to operationalise. It requires a framework on which decision can be made about the child's and family's needs for services. To date two scales have been used in Northern Ireland; namely the 'National needs assessment tool for long term ventilated children in the community' - Bradford continuing care (used by Royal Belfast Hospital for Sick Children) – and Leeds Nursing Dependency Score (used in Homefirst HSS Trust and elsewhere). Table 2 gives an example of the different criteria that can be used to determine eligibility for additional support and examples of the form this may take are also provided. Appendix 3 gives details of other criteria that might be included.

However members of the Project Board and Steering group along with practitioners we consulted, felt that none of the existing scales were adequate. Nonetheless they recognised the need for a common instrument to be used throughout Northern Ireland so that the inequities that exist in access to services might be addressed.

Recommendation
Services should work to develop an assessment instrument that can be used to determine a child's physical healthcare needs and their family's need for additional support services (including respite breaks) and to assist with reviews of their needs. This would be used by all HSS Trusts, Education and voluntary organisations in Northern Ireland.

This would form a discrete piece of work that could be commissioned by the Department in conjunction with the Health and Social Care Authority.

A number of further points were noted in arriving at a definition and assessment framework.

- The definition has to embrace the impact of family circumstances on children and young people and parental needs for support.
- The assessment would embrace a range of settings, including school.
- An absolute definition is not achievable but rather it is best termed as probabilities, based as it is on professional judgements.

Table 2: Examples of items common to Bradford and Leeds Scales

Criteria	***High probability of additional support needs required***	***Examples of support options that would help***
Breathing/Airways	Total ventilator dependence/ Oxygen dependent/episodes of apnoea	Trained staff needed to assess and monitor Carer training completed and monitored
Feeding	Total parental nutrition - Tube-fed (Gastronomy/Naso-gastrically) Complex feeding regimes including TPN or overnight nasogastric feeds	Trained staff needed to assess and monitor Carer training completed and monitored
Epilepsy	Major seizures – daily/ Seizures require acute medical interventions	Medication reviewed regularly – blood tests; EEGs
Mobility	Immobile over 5 stone/requires two people	Necessary equipment /adaptations installed at home
Carer	Main carer has physical illness; mental health issues; learning disabilities	Counselling for carer; domiciliary support and shared care arrangements
Siblings	Another sibling has chronic illness/disability	Domiciliary support; sitting services Daytime breaks: family placements; overnight stays
Child Protection issues	Grounds for concern	Shared care arrangements
Child has mental health difficulties	≥ 20 risk factors identified and / or ≤ 4 resilience factors present..	Specialist mental health services
Child has sensory impairments	Moderate/profound sensory impairment / which affects ability to function relative to age	Provision of aids

- The decision to classify a child or young person as having complex needs that require additional support should be taken by a minimum of two or a team of professionals in conjunction with the parents.

- Moreover the designation of having ‘complex needs’ is not fixed but is variable and needs to be regularly reviewed; i.e. children can have complex needs for a period of time.

Understanding the Needs of Children in Northern Ireland (UNOCINI)

Preliminary studies are underway to develop and implement a standardised approach to carrying out an assessment of a child's and their family’s additional needs and deciding how those needs should be met. It is intended that “the UNOCINI will assist with a more effective, earlier identification of additional needs, particularly in *universal services”* (emphasis added). “It should provide a simple process for a holistic assessment of a child's needs and strengths, taking account of the role of parents, carers and the impact of environmental factors on their development” (DHSSPS, 2007’ p.29).

It is likely that UNOCINI will not capture the specific needs of children with complex physical healthcare needs hence the assessment instrument proposed for these children and families could form an additional module of the UNOCINI. Certainly the ethos underlying both approaches appears very similar.

Agreement on ages

At present variations exist throughout Northern Ireland as to the upper age at which young people can access children's services. For example children may transfer to adult wards in acute hospitals at 14; they may transfer from community children's nursing between 16 and 18 years; they may no longer qualify for children's respite services at 16 years of age and they may leave school at 16 years.

A standard age cut-off is recommended for all health and social services and it is proposed that the Children Order definition is followed, i.e. children up to 18 years of age. However a child may remain in a special school for the whole of the school year in which they become 19 years. In this instance some tolerance should be permitted for the continuation of children's services.

The age extension to 18 years will have implications for certain community services but more especially for acute hospital provision. Discussions will be required with consultants and nursing staff about the best location for the care of teenagers aged 16 to 18 years of age.

As a marker for the future, more of these children will survive into adulthood and plans need to be made now for suitable provision for their needs, especially within community nursing services serving adult persons. This was beyond the scope of the present project although certain of our recommendations around nurse training do take this into account.

However a planned transition from children's services is an issue that must be addressed. Best practice suggests that this planning should commence at 14 years of age so that new service arrangements can be developed as required.

Estimated Numbers

At present we do not have an accurate count of the number of children in Northern Ireland who meet the proposed definition of physical healthcare needs and as explained above it may not be possible to arrive at an accurate count although estimates could become more precise if a common instrument was used.

However an attempt was made to gain some insight into the numbers of children in Northern Ireland. Using data obtained in surveys conducted by Homefirst HSS Trust and in SHSSB area and information gathered in Merseyside (Merseyside and Cheshire Cancer Network, 2004), we estimate around 250 children in Northern Ireland would require active support at any one time with around 250 liable to make demands on services and require some form of ongoing support. This gives an estimated incidence of one per thousand children although anecdotal reports suggest that this rate can vary markedly across different geographical areas.

However certain children with complex physical healthcare needs are liable to require high cost packages. The total amount spent by HPSS in recent years is not easily determined from existing information sources as they can be drawn from various programmes of care.

Existing information systems in HPSS and Education do not identify these children and families. Possible improvements could include:

- Resourcing Module V of the Child Health System so that they can be recorded by community paediatricians and reports on numbers made available to Trusts;
- Ensuring the proposed disability register under the Children Order identifies these children. However some families may prefer not to register their child as 'disabled'.

- Assessment and statementing information obtained by Education and Library Boards could also be used to identify these children. However a change would be required to present recording systems for this to be done.

More broadly, issues around the sharing of personal information across agencies will also need to be addressed as will the duplication inherent in maintaining these different information systems.

‘End of life’ needs

Finally, the proposed definition may not identify the particular needs of children at the ‘end of life’. For these children it is proposed that the Care Pathway produced by ACT (The Association for Children’s Palliative Care: 2004) be adopted in Northern Ireland. It is proposed that community children’s nursing service should take responsibility for co-ordinating its implementation on a multi-disciplinary basis within their Trust area.

Section 4: Existing services

As the Project progressed it quickly became apparent that sizeable numbers of professionals are involved with this client group. Figure 2 lists those named by the Project Board, Steering Group and professional focus groups (see below). These are divided into four main service systems but they are arranged in terms of parents' experiences in the interviews undertaken with them as part of the project (see later).

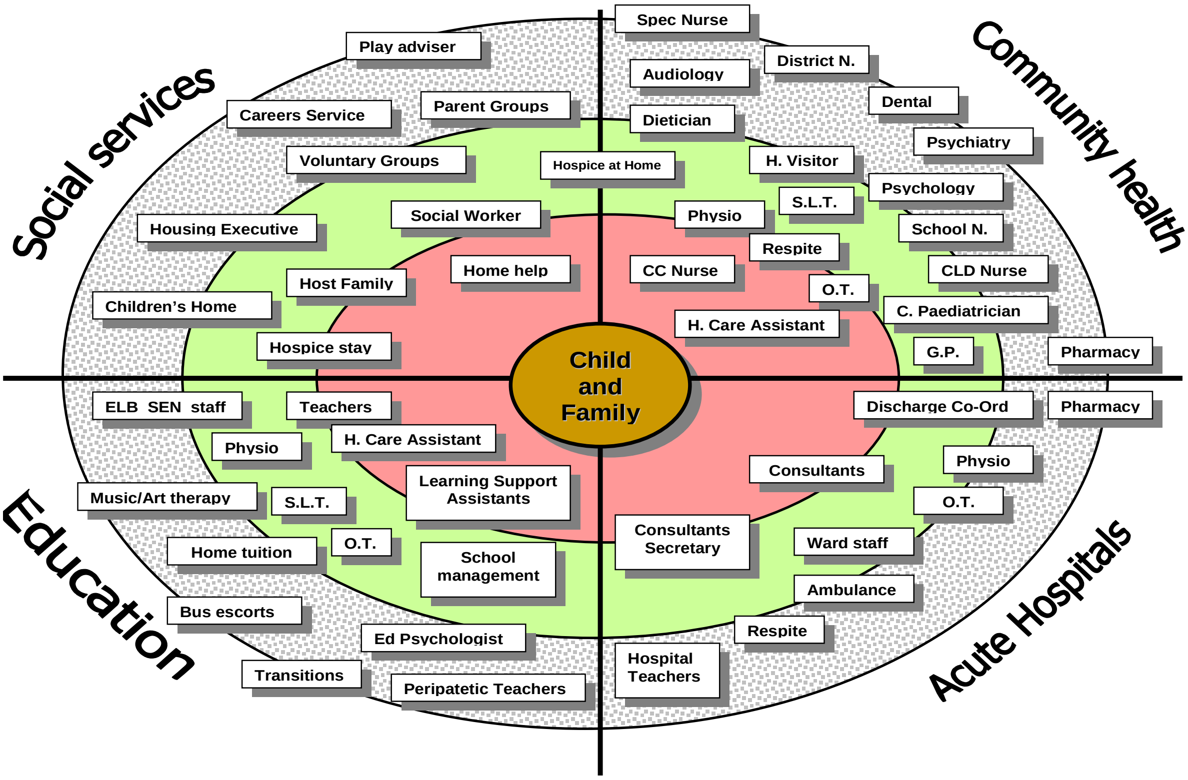

Figure 2: Professional involvement with children and families

Some points of note:

- Those named within the inner circle are those with whom parents report closest links and contact.
- Those named in the middle circle are people with whom they have ongoing contact to varying degrees or with whom they had significant contact in the past (and may again in the future). Those staff who overlap into the inner circle, tended to have significant contact for some parents.
- The outer circle is for those persons who were identified by professionals as having an involvement with these families, but they were not mentioned by any of the parents interviewed. This is indicated by being placed on the outer part of the circle. Those overlapping with the middle circle were mentioned by a few families as having had contact in the past due to particular circumstances.
- Some professionals may be employed by one system but work predominantly in another (e.g. healthcare assistants, therapists working in schools but employed by HPSS). Also staff from the same discipline can be employed by different systems to work with the same family at different stages of the child's life.
- This map does not show other groups that could be of significance, such as community associations and the politicians at local council, NI Assembly or Westminster.

Of course, the detail of this map will vary from family-to-family depending on their needs and the availability of services in their locality. This generalised service map illustrates how existing services have tried to respond to the needs of a new client group that has emerged over the past two decades. In many ways their responses were ad hoc and piece-meal with no strategic planning nor dedicated financial resources provided. The result is a delivery system that is inefficient even if it does manage to be effective – at times.

- It is inefficient economically, e.g. there is duplication of resources.
- More crucially it is inefficient of human effort and emotions. Energies are diverted into managing conflict, responding to crises, patching together fragile responses.

Another approach would be to develop an individualised, family-centred service plan within an overall service framework. This is recommended for all children with special needs but if it even more imperative when sizeable numbers of professionals and services are involved.

Recommendation
A service map as per Figure 2, should be created for each individual child and family and shared with all services and persons who have an involvement with them. Names and contact details should be provided of all those included in the map.

An individualised plan would identify:

- Those people who have greatest involvement with the child and family at present. The accompanying plan would describe how they co-ordinated their support.
- Those personnel who may have more peripheral but significant contact with the family. The accompanying plan would identify how they are kept informed.
- Those professionals and services that are absent for the child and family. This would raise questions about equity and need.

It is likely that nursing would be an integral feature of every plan although this process would help to identify those nurses who are (or need to be) involved and the co-ordination of their inputs.

Service systems

Figure 3 illustrates the various systems in which staff are employed. The five new

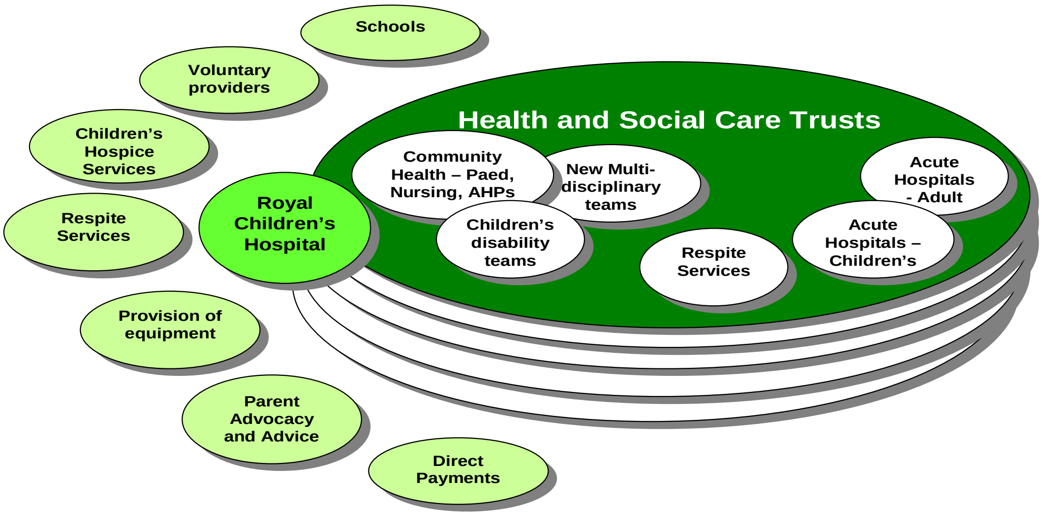

Figure 3: The different systems involved in service delivery

Health and Social Care Trusts have the major role in service provision although it is not altogether clear how the six different facets of their provision will be managed under the new arrangements. There is the possibility that nursing services across community services and acute hospitals can work in a more co-ordinated manner.

The Royal Belfast Hospital for Sick Children is identified separately because of its regional remit.

There are a number of other significant service systems that often operate in isolation from one another. As the Figure shows these include voluntary providers although the services provided by the Children's Hospice has been identified separately as it serves all of Northern Ireland whereas other providers may have a more local remit. (NB These include care at home and an additional residential facility as well as the Hospice in Newtownabbey.)

Nurses may be employed in a number of these services such as the Children's Hospice and respite provision. They can also be employed on a part-time basis by families using Direct Payments.

In Section 6 of the Report recommendations are made for better co-ordination among service systems.

Nursing responses

Figure 4 illustrates the range of nurses who have an involvement with the children and their families.

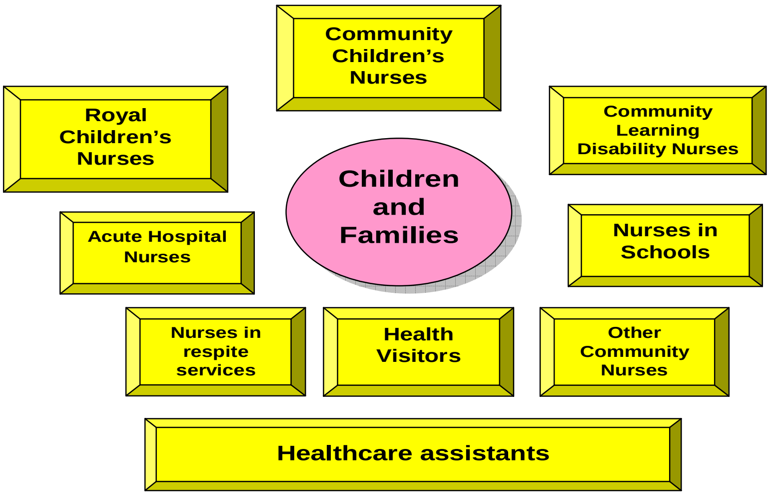

Figure 4: Nurse involvement with children who have complex physical healthcare needs

Community services

The main involvement in the community tends to be with community children's nursing (CCNs). An accurate count of those currently in employment is not available but it is estimated that there are around 30 in post at present, although the size of the teams does vary across HSS Trusts.

In addition other community nurses may have an involvement, notably community learning disability nurses (Regional Forum, 2007). This is especially so for children with associated severe learning difficulties and who may co-work the nursing care with the CNN or receive re-referrals from the CCN when acute episodes of care have stablised. Other community nurses also include district nurses who may provide weekend cover or specialist nurses for diabetes or epilepsy. Palliative care nurses may also have an involvement with some families.

In some special schools, a nurse is based full-time although this happens in only certain HSS Trusts.

Health visitors provide little hands-on care for the child and there involvement with the family is reported to be more of a support for the mother. Along with other nurses they may also fulfil child protection responsibilities.

Acute services

Many children and families have an ongoing contact with nurses in the acute hospitals, both the Royal Children's and the Area Hospitals. Many children have frequent admissions to hospital and arrangements are often in place for them to by-pass A&E and to go straight to the children's ward. Parents may also telephone the ward to get advice about possible admission. A nurse may also act the discharge coordinator for the child and family.

Similar arrangements are required for adult wards but these are likely to be in place.

Nurses are also employed in the Children's Hospice which provides respite breaks for children and families and also in respite facilities provided by statutory and voluntary organisations. Indeed these children cannot be safely placed in respite homes without adequate nurse cover and this reduces the availability of respite breaks for these parents.

Parents also reported that nurses from the acute sector also worked as bank staff to cover shifts in community services.

Finally concerns were expressed about a shortage of paediatrically trained nurses within Northern Ireland and that insufficient numbers were in training.

Healthcare assistants

Increasing numbers of healthcare assistants are now employed in both sectors although the total number is not recorded. They work under the supervision of a nurse and are deployed in family homes and classrooms. However there are disparities around Northern Ireland in their terms and conditions and issues around legal liability need to be clarified.

Recommendations around improvement in nursing services are presented in Section 6.

Section 5: Views of Parents and Practitioners

Two major studies were undertaken as part of the Project. One documented the experiences and views of parents in Northern Ireland obtained through personal interviews. The second gathered the opinions of practitioners to present provision and their suggestions for improvement.

The views of parents

Service personnel passed on to prospective parents an invitation letter on behalf of the Project team. In all 34 parents volunteered to participate. Face-to-face interviews were conducted with 15 families and with a further 15 families were interviewed by telephone; a completion rate of 88%.

Parents came from all over Northern Ireland and the full age range of children was covered with upwards of 20 different conditions reported and 16 invasive procedures being conducted by family carers.

The children had a range of technological supports and other requirements that required the parents to undertake a variety of invasive procedures. These were:

Peg Tube feeding
NG tubes
Duodenal Tube
Tracheotomy
Suction
Oxygen
Shunt

Illiostomy bag
Portacav
Rectal Valium
Buccal Midazolam (epilepsy)
Nebuliser
Mini-button

Catheter
Bi-Pap
Insulin injections
Insulin pump
Blood tests

Information was gathered about the care tasks that parents undertook with their child; the support they received from professionals and services; their experiences of education and respite breaks, the services they had found most helpful and the reasons for this; the negative experiences they had encountered and their advice to other families. A full report of the findings is given in Appendix 4.

Talking with the parents was a humbling experience. They came from all walks of life: ordinary people called to become exceptional parents. Their challenge was to provide the specialist assistance that kept their child alive while being a mummy and daddy to their much loved child. In essence, they wanted and needed support to maintain this balance. Among the key messages that families felt needed to be heard by service planners and providers were:

- They wanted their child to be part of the family; stays in hospital should be minimal.
- Caring for the child had had a major impact on their lives: moving house; marital separation; giving up careers; financial difficulties; illness and stress.
- A recurring theme in talking with parents about services was the fight they had in order to get the help and support they needed. Parents talked about “battles” and “being in the trenches”.
- Building up a trusted relationship with service personnel was seen as the best form of support.
- Community children’s nurses were mentioned as being the most helpful.

- Families spoke of the very limited amount of time they were given for respite breaks and they could do with more. They wanted residential facilities to be available locally for their children to stay.
- Getting appropriate equipment was the thing that made the biggest difference for them even though the costs were small. Delivery times were protracted.
- Their advice to other parents was to remain in control; decide who comes to their home and stand by what you believe is best for you and your child.

An interim report on the findings from parental interviews was shared with the Project Board and Steering Group and a copy was given to all participants in the Round Tables. They felt that the main messages were similar to those they had encountered in their services which suggests that the sample validly represented the broader parent population.

The views of practitioners

The views of practitioners were sought in three ways. First, a total of 52 professionals drawn from a range of services across Northern Ireland attended one of four focus groups. Two groups were exclusively for a range of nurses in community and acute settings; and two were for personnel from a range of disciplines including nursing. They were facilitated by two members of the project team.

The groups were asked to focus on four issues.

- Confirm the professionals and services involved in supporting children with complex physical health needs and their families.
- Confirm the list of issues facing nursing services at present when seeking to support children with complex physical health needs.
- Give examples of developments within local services which could be built upon
- Propose creative solutions to overcome challenges in service provision at present and priorities for service development

A report detailing the information gathered was prepared and circulated (see Appendix 5).

Self-completion questionnaire

The information gained in the focus groups was used to frame a self-completion questionnaire that the Project Steering Group scrutinised and revised. The questionnaire consisted of 51 recommendations for service improvements; grouped into six sections that reflected the core themes to emerge from the focus groups and parent interviews. The themes and sample items are given in Table 3. The questionnaire was widely circulated throughout HSS Trusts, acute hospitals, children’s disability teams, education and library boards, special schools and major voluntary providers.

The aim was to identify those recommendations on which a broad consensus existed and those that deserved to have priority. Respondents were asked to indicate the extent of their agreement with each recommendation by choosing one of five options from strongly agree to strongly disagree. Secondly, respondents were asked to prioritise the recommendations by selecting for each theme, one or at the most two recommendations that they felt should have priority. These would be ones that they feel will make a real difference and which should be implemented immediately.

Responses were received from 159 respondents from a range of disciplines and services. In all 81 identified themselves as nurses or healthcare assistants with 54 non-nursing

Table 3: The recommendations receiving highest agreements and priority rating.

Recommendation	SA	A	N	D	SD[1]	Priority (N=135)
Theme 1: Co-ordination of services locally						
An accessible information booklet should be developed for parents and professionals that signposts where information can be found about hospital and community services for children with complex physical health needs.	86%	13%	1%	-	-	19
Each child with complex physical health needs should have one key worker who is the main point of contact across all health and social services supporting that child.	66%	28%	4%	2%	-	56
Theme 2: Co-ordination of services regionally						
An overall service framework should be put in place for children with complex physical healthcare needs across Northern Ireland that outlines minimum standards and regional procedures.	58%	39%	3%	-	-	39
Regional procedures should be put in place to plan for the transfer from 14 years of children with complex physical health needs to adult services in the community.	61%	31%	2%	3%	2%	29
Theme 3: The need for equity in service provision						
Any assessment of the dependency of a child should also include an assessment of the capacity of parents and families to cope with care required.	64%	32%	2%	1%	1%	45
An out-of-hours service by community nurses for children with complex physical health needs should be provided throughout Northern Ireland.	49%	38%	10%	3%	-	41
Theme 4: Developments in respite (short break) provision						
Locality-based, nursing-led, respite care facilities should be developed to support children with complex physical health needs* *(Nurses more strongly agree 77%).*	66%	28%	5%	1%	-	39
4.8 Staff working in existing or planned respite facilities should receive training in the care for children with complex physical healthcare needs.	71%	26%	2%	1%	-	32

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[1] *Strongly agree (SA)* – would mean that you have no reservations at all and consider this to be essential; *Agree (A)* – you may have a few reservations but on the whole you feel this is worthy of support.; *Neutral (N)* – means you have no strong feelings one way or the other or that you do not sufficient information on which to make a decision.; *Disagree (D)* – means you have reservations about the recommendations or feel it is unlikely to lead to any benefits; *Strongly disagree (SD)* – you have major reservations and feel it will not lead to any benefits.

Table 3: The recommendations receiving highest agreements and priority rating (contd).

Recommendation	SA	A	N	D	SD	Priority (N=155)
Theme 5: The provision of education for professionals and family members						
Health Care Assistants in community settings should be appropriately trained (e.g. to NVQ Level 3) with access to regular top-up training	66%	28%	6%	-	-	35
A budget for education and training of staff in relation to caring for children with complex physical health needs should be identified and ring fenced.	57%	36%	7%	-	-	34
A training needs analysis should be undertaken across Northern Ireland to identify the major areas of deficit in knowledge and skills among professionals who work with children with complex physical health needs and their families.	49%	43%	6%	1%	1%	34
Theme 6: The views of children and their families						
Parents need to given a clear and realistic indication of the supports that will be available to them on discharge from hospital and the demands likely to be placed on them.	79%	20%	1%	-	-	73
Active steps should be taken to increase the involvement in service planning of family carers of children and young people with complex physical health needs.	49%	47%	4%	-	-	41

personnel such as doctors and therapists (N=16); social service staff (N=9) and educational personnel (N=30).

Table 3 summarises the recommendations that had the highest level of agreements and those which most respondents identified as a priority out of the 159 respondents. Appendix 6 details all the recommendations and the ratings given to each.

There was a marked degree of unanimity around the majority of recommendations. This suggests that respondents irrespective of their discipline or location had come to common conclusions as to what would help the children and their parents. Indeed respondents noted that some of them were already implemented in their area. It was not clear why this had not happened in other areas or indeed why other recommendations had not been acted on that did not seem unduly difficult to implement. These and other issues were explored in the third phase of consultations with practitioners.

Round Table Meetings

Invitations were extended to service mangers and commissioners across a range of agencies to attend one of two meetings held in Omagh and Antrim. Nearly 40 people participated from different HSS Trusts and Boards but also from education and voluntary agencies. The aims of the Round Table were:

- To feedback on the work of the project in terms of information obtained from parents, front-line service staff and the literature reviews;

- To elicit comment on the proposed models and systems emerging from the above.
- To explore the implementation issues that arise from the above with personnel who likely will have responsibility for these.

A briefing sheet was distributed prior to the meetings along with the two reports outlining the views of parents and practitioners. Diagrams similar to Figures 2 and 3 were used to summarise the systems and issues that had been identified by the Project up to that point along with a listing of pertinent issues for nursing services in particular.

The task set for the participants was simply stated: we knew **WHAT** needed to be done but we were less clear about **HOW** these developments could come about and **WHO** could make them happen.

At the round tables, discussion took place in smaller groups with participants drawn from pertinent backgrounds. Different groups focused on one of three broad themes:

- Commissioning arrangements and guidance;
- Co-ordination of service delivery at provider level.
- Nursing services for children.

A recurring theme was the uncertainties that presently exist because of RPA. This made it difficult to identify with certainty the agencies and people who had an involvement in service improvement.

Also it was felt that the needs of this client group could have low priority in these times of change. The counter-argument was that the anticipated changes provided a much better context for dealing with issues and a prepared plan assisted the new agencies by defining a role for them.

Appendix 7 details the recommendations that emerged in the discussions. Once again there was a high degree of unanimity about what needed to happen and how the recommendations might be achieved.

The views of participants in the Round Tables have shaped the recommendations described in the next section of the Report.

Section 6: Recommendations

The recommendations have been grouped into three main themes.

1. Commissioning of services
2. Service delivery improvements
3. Nursing responses

However they are inter-related in that progress in one area will help to drive change in another. Nonetheless it is possible that certain improvements can be made within one area despite lack of progress in another.

A number of key proposals have been identified, although many others were suggested by informants during the course of the Project. It is our judgement that the proposals we have nominated will subsume others and if implemented with create the conditions for tackling others.

1. Commissioning Recommendations

Recommendation
A specific service framework should be produced for families and children with complex physical healthcare needs that is multi-agency and multi-disciplinary.

There was unanimity on the advantages of having a common framework for services within Northern Ireland. This would set the standards expected from services; ensure greater equity in access to services and more consistency in the supports that would be available to children and their families. It would enable deficits in current provision to be planned and costed. The framework would have the potential in to promote cross-sector working (e.g. between acute and community services) as well as encouraging multi-agency approaches.

It was felt that a specific service framework needed to be within the context of an overarching framework for children and families. The National Service Framework for Children, Young People and Maternity Services produced by the Department of Health (2004) for England provides a possible example of this, This could be readily adapted for Northern Ireland with perhaps more cognisance given to our joint Health and Social Services Structures and greater involvement of Education.

Table 4: Issues to be covered by the proposed service framework

Definition	Hospital-community liaison
Assessment of need	Healthcare assistants
Family supports	Managing transitions
Core groups of professionals	Workforce planning
Co-ordination of services	Joint planning and funding

The English framework contains Standard 8 that focuses on disabled children and those with complex health needs; Standard 6 that deals with children and young people who are ill and Standard 7 that looks at children and young people in Hospital.

What is proposed for Northern Ireland is one framework document that is focussed on all the differing support needs for children and young people with physical healthcare needs from birth up to 18 years of age. Hence it would integrate the recommendations that in the English framework are tackled thematically and tailor them to the needs of this specific group. The primary rationale is that these children above all others require coherent and co-ordinated responses that can be of high cost to HPSS and Education.

Table 4 summarises some of the issues that a service framework might cover. As noted in Section 3, further work is required to develop an assessment instrument that would closely link with the service framework.

Recommendation
Services should work to develop an assessment instrument that can be used to determine a child's physical healthcare needs and their family's need for additional support services (including respite breaks) and to assist with reviews of their needs. This would be used by all HSS Trusts, Education and voluntary organisations in Northern Ireland.

Also it would be important to develop procedures and protocols relating to staffing and coordination of services with particular attention being given to the management of transitions between services as well as at different stages of the child's life.

Many of the recommendations developed in the Project (see Appendix 6 and 7) would likely be included within the proposed Framework. Hence a great deal of the preparatory work has been accomplished. Given the centrality of nursing within service provision in this group, it seems appropriate for the Chief Nursing Officer to progress this work.

Although the production of such a framework had wide support, it was less clear how the framework would be achieved. Discussion revealed some of the complexity of the issues that require consideration. These were:

- Joint planning must be undertaken by DHSSPS and the Department of Education. The existing interdepartmental committee on special education needs might consider establishing a subgroup to specifically address this issue. The review of special educational needs by DE is also nearing completion and may provide another context for joint working. Moreover there are local experiences of joint working between Boards and ELBs, notably in the Southern Board area to guide this work (SHSSB/SELB, 2005).
- The new Health and Social Care Authority will have a major role to play in the future commissioning of services. Likewise the proposed Education and Skills Authority will likely attempt to bring greater equity to educational provision across the existing Education and Library Board areas. Both bodies are likely to be involved with the commissioning arrangements inherent in the Service Framework. The two departments will need to ensure that the two authorities apply the framework in their commissioning.
- The nursing response to families and children with complex physical healthcare needs should be defined with the service framework. There appears to be a degree of unanimity on the form this should take. To date though, there has not been a co-ordinated response to children's health within DHSSPS and no recent review of children's nursing services.

- The preparation of these frameworks and reviews should be inclusive and participative (e.g. with voluntary sector involvement) but equally they should be done within a short time frame. A ‘bottom-up’ as well as ‘top-down’ approach is required to gain ownership.
- A care pathway approach may work well in caring for children at ‘end of life’. However there was less support for care pathways in general being applied to this group of children given the variety of conditions that come under the rubric of ‘complex physical healthcare needs’.
- The frameworks will provide the standards against which services will be assessed by the RQIA. It is not clear what function, if any, they need to have in the development of the Frameworks.
- Given the high cost of certain packages and the low incidence of their occurrence in any one year, there may need to have regional commissioning of health and social services for children with PHC but they should be delivered locally. Alternatively a contingency fund could be held centrally which Trusts can draw down according to need. The framework could address the issue.
- Local Commissioning Groups have a key role on identifying inequities across Northern Ireland so that commissioning can be adapted to local needs. However it is not clear how this will be achieved nor whether Children’s Services Planning by HSS Boards will continue.

Two further commissioning recommendations were strongly endorsed by our informants.

Review of equipment

DHSSPS needs to instigate urgent reviews of the commissioning and delivery of equipment (e.g. hoists, frames) to children and families. This review must involve education.

The recently commenced review of wheelchairs that is lead by the SHSSB, should give specific attention to the needs of children.

The provision of aids and wheelchairs is one of the pressing concerns and frustrations experienced by families and professionals. Yet the provision of appropriate equipment (often at relatively low cost) in a timely way, was the thing that made most difference to family life. Various accounts told of inefficiencies and waste in present arrangements. Equipment is an integral part of the nursing response yet it is often beyond the control of nurses to effect the necessary improvements as they do not have access to a dedicated equipment budget.

Review of respite provision

DHSSPS and the HSC Authority need to urgently review respite provision for children with special needs; particularly with respect to nurse involvement as this is deemed necessary for children with complex physical healthcare needs. This review should involve education.

The overall dearth of respite options in Northern Ireland has been widely reported in research papers (e.g. McConkey and Adams, 2000) and policy reviews (e.g. Equal Lives, 2005).

Moreover there are particular issues around the registration of residential respite homes as ‘children’s homes’. We were given various examples of families being turned away from facilities on the grounds that they were unable to manage the risks these children presented. Arguably these parents are the very ones who are most in need of respite breaks. Hence the review needs to look at issues around registration and inspection of respite services as well as age range of children covered (i.e. up to 18 years); the transition options available in adult services and assess the need for increases in the number of places.

The outcomes of this review would also have major implications for nursing and yet it is an issue that nursing per se cannot take forward.

Service Delivery recommendations

The service framework will provide the overarching context for service delivery. This will continue to take place across a range of agencies. The five new Health and Social Care Trusts will continue to provide the bulk of services and their advent may provide an opportunity to achieve greater service cohesion than has been the case thus far among the various service domains they cover (see Figure 3). However voluntary providers will continue to have an important role to play as will educational services. A priority is to ensure better co-ordination among these services.

Recommendation
Each family should be allocated a member of staff who will act as the main point of contact for the family and the co-ordinator of service inputs.

The co-ordinator will be the professional who has most ongoing contact with families and will sign-post them to services and well as acting as a conduit of information for other services. In many instances community children’s nurses will continue to fulfil this role although this may need to be made more explicit than at present. It is possible that this person could come from voluntary as well as statutory provision.

A core feature of their role is to assist with the planning of transitions in the life of the child, for example from hospital to home; from home to school entry and transfer to adult services. It is likely that the co-ordinator will be part of the proposed core group of professionals who have most contact with the child, such as teacher, therapist, social worker or nurse. It is suggested that this core group would meet regularly with parents to review service plans. These two proposals should ensure that no child with complex with physical healthcare needs should ever be on a waiting list for services, as their needs will have been identified and planned for well in advance.

However there a number of considerations in relation to the proposed co-ordinator role.

- Under the Children Order, a child who spends more than 90 days away from the family home is deemed to be a ‘Looked After Child’. Usually a nominated social worker has responsibility for convening regular LAC reviews which involves co-ordinating the inputs of various professionals to this process. It is anticipated that they would continue to exercise this discrete function. This arrangement would provide families with access to a health contact as well as a social services contact.

- There may be scope to combine the role of co-ordinator with some of the functions of care manager if this model is used within children's services. For example, there would be advantages in co-ordinators having access to budgets that can be used to provide emergency respite or augmented home supports on a short-term basis. This could be channelled through nursing budgets as bank/relief staffing.

Two further significant recommendations are urgently required to improve services.

Healthcare Assistants

Recommendation
A common policy should be developed by HSS Trusts and Education and Library Boards (Education & Skills Authority) regarding the employment of healthcare assistants.

A primary source of support for families is from personnel who can provide competent 'hands-on' care to the child in home, school and respite setting. In recent years, healthcare assistants have been trained and deployed in various settings although issues still remain about these posts; such as level of pay, roles, accountabilities, contracts and training.

HSS Trusts and ELBs need to come to an agreement about joint funding of posts within school settings. Moreover the roles of healthcare assistant and learning support assistant should be combined for certain children; the so-called 'hybrid worker'. Already there are effective arrangements in place within Trusts that could be emulated throughout Northern Ireland although more work needs to be done with respect to governance issues.

Mechanisms also need to be found so that healthcare assistants employed by one agency can easily transfer to another, for example between HSS Trusts, between ELBs and Trusts, or between voluntary sector and Trusts. At present, the lack of these mechanisms can mean long delays in filling posts and providing continuity of employment to well-trained assistants.

Nursing has a key role to play in the training and supervision of these staff. They can be considered within the revised skill mix in the nursing workforce.

Greater choice of respite options

Recommendation
An increase is needed in local respite options for these children and families.

In addition to the commissioning review of respite provision, there is an urgent need to address the particular dearth of facilities that can offer either emergency care of the child on a short-term basis or planned breaks so that parents can have a respite during the day or overnight. Failure to do so can mean unnecessary hospital admissions with the attendant risks to the child and family well-being.

A range of options are required in order to meet family preferences and there are examples of good practice available from around Northern Ireland, such as 'Hospice at Home', relatives acting as paid replacement carers, and the Children's Hospice. These options need to be available in all areas and not be dependent on short-term funding as is the case at present.

Although families may use Direct Payments to fund their respite services, this option depends on suitable personnel (i.e. nurses and healthcare assistants) and services being available for them to avail of.

Given the needs of the children, it is likely that trained children's nurses will be required in the staffing of respite services, especially those where the child stays overnight. Hence workforce planning for nursing children must take account of this service need.

Nursing Recommendations

It will be possible to define more definitively the nursing response to these children and their families when there is greater clarity around the commissioning of services and improvements to service delivery systems. Nonetheless it is apparent that two recommendations should be implemented immediately.

Recommendation
Each new HSS Trust should undertake an audit of nursing services for children with particular respect to future roles and functioning of children's community nursing; the interface it has with the acute sector and with other community nurses, notably leaning disability nursing. Voluntary services also need to be included.

Children's community nurses began to be appointed in the latter part of the 1990s. The numbers in post are still small and resources were not available for out-of-hours cover at evenings and weekends. Moreover little consideration appears to have been given to the impact these appointments would have on other community nursing services, notably community learning disability nurses but also district nursing and school nurses.

Similarly there appears to have been little explicit acknowledgement of the interface with acute hospitals despite many of the nurses having been recruited from the hospitals. The new Health and Social Care Trust arrangements may make it easier for Nursing and Children's services to span these two domains.

The proposed audit should be done speedily as much of the information should be readily available and indeed the new directorates may be eager to have it. The CNO could negotiate the time-frame in conjunction with the CEO of the Trusts.

The audit should consider related issues such as 24 hour emergency cover, partnerships with the voluntary sector; options for emergency respite provision outwith hospitals; flexible working across acute hospitals and community children's nursing; discharge planning procedures; the transfer to adult wards in acute hospitals; transfer between community nursing services and a review of innovative practices such as telemedicine.

The outcomes of the audits would be essential for workforce planning and the commissioning of increased numbers of children's nurses. The consensus appeared to be that there were insufficient pre-registration training places for paediatric nursing.

Training for nurses and healthcare assistants

Recommendation
Accredited core training in specific procedures needs to be available regionally for nurses and healthcare assistants (e.g. provided by a peripatetic training team). This core training could then be individualised for specific children according to their needs. Opportunities should be given to parents to avail of this training.

The life of children with physical healthcare needs is often dependent on a range of sophisticated technical procedures. However the numbers of children requiring each procedure can be small at any one time. As noted in Section 3, parents can become adept in using these procedures but they, along with healthcare assistants and nurses who have no previous experience of certain procedures, require training in their use. The latter are those nurses and other professionals who may come into contact with the child, e.g. in respite or school settings. At present this training can be ad hoc and it would be more cost-effective for this to be provided on a regional basis, perhaps by a small peripatetic training team.

The availability of such training opportunities would increase the number of trained personnel who would be able to meet the needs of children with complex PHC needs, e.g. it would also provide a common training for healthcare assistants and increase their employability across a range of children.

This training could also be made available to parents, respite carers and other personnel who may come into contact with the child, e.g. community activities and clubs. This should also include access to other pertinent courses such as back care and manual handling.

Certain procedures would need to be particularised for individual children but training in these could be given to the personnel involved with that child, e.g. those in acute hospitals.

Further issues for consideration

A number of ‘cross-cutting’ issues arose during the project that need to be considered in any further work within the three areas detailed above; namely commissioning, service delivery and nursing responses. They are summarised here so that their importance is noted although it was not immediately apparent how they could be taken forward.

Voice of parents and children

The opinion and aspirations of parents, and were possible that of the children and young person, must be reflected in all decision-making. This is easiest to do at the level of the individual family. However it important that their voice is included in commissioning and service delivery. This might be done through engagement with existing parent groups such as the newly formed Northern Ireland Parent Carer Council (NB This has grown out of the group formed in the SHSSB as part of the Wraparound Project.) At present the Northern Ireland Children’s Commissioner has commissioned research on the advocacy of children and young people with complex needs. This may yield further ideas and proposals.

Ethical and legal issues

Children with complex physical healthcare needs pose various ethical and legal dilemmas in service delivery; for example protocols and permissions around non-resuscitation. These sorts of issues have received sparse attention within this Project although they will continue to feature of practice in this area for many years to come. Nursing personnel need to be aware of them and enabled to make informed contribution to these debates.

Local coordination of services

The emphasis in this report has largely been on centrally driven initiatives. Within these is the need to define how local coordination (e.g. at a Trust and sub-Trust level) can be achieved across sectors (e.g. with education and HSS), and in particular how existing inequities will be addressed.

Drivers of change

A major concern among informants is that the needs of this client group will be forgotten among the many other pressing demands within health and social care. Comment was made about how children's health issues have not had a priority within the DHSSPS and it is not clear how the new Health and Social Care Authority will handle the commissioning of children's health services. One proposal is the appointment of a regional co-ordinator of health services for children within the DHSSPS and/or the Health and Social Care Authority.

Financial resources

Services to this group of children and their families are currently under-funded although it is not possible to put a figure on the deficit. Equally demand is likely to increase as children survive for longer and more children are born who require complex physical healthcare throughout their life. Part of the recommended actions will enable more accurate costings to be derived but acquiring the necessary resources to implement them will remain a challenge.

Individualised payments

Although direct payments have the potential to give families more choice and control of services, further work is needed in order to make these schemes work better for families. In part it is a matter of educating service practitioners as well as parents about how the schemes can operate in practice. More fundamentally training a suitable workforce whom parents can employ is essential and this must be factored into any workforce planning.

Summary of core recommendations and implementation

Table 5 summarises the core recommendations emerging from this study. More detailed recommendations are noted in the survey of professionals (see Appendix 6) and in the report of the Round Tables (see Appendix 7). These could be subsumed within the recommendations listed or would follow on when those noted above are implemented.

Action Plan

Following acceptance of the Report by the Board of DHSSPS, the following actions were agreed for taking forward the implementation of the recommendations.

1. The Report is considered and endorsed by the Department of Education.
2. A project group is formed from the membership of the existing groups - with augmentation as required - to oversee the implementation phase.
3. A specific service framework for children with complex physical healthcare needs is developed for Northern Ireland.
4. A single assessment tool for identifying and assessing children with complex healthcare needs is developed for use by services in Northern Ireland.
5. An audit of nursing services to children is undertaken in the five new Health and Social Care Trusts.

Table 5: Summary of key recommendations

- A specific service framework should be produced for families and children with complex physical healthcare needs that is multi-agency and multi-disciplinary. This must cover transition arrangements from acute hospitals to community; school entry, school transfer and school leaving.
- Services should work to develop an assessment instrument that can be used to determine a child's physical healthcare needs and their family's need for additional support services (including respite breaks) and to assist with reviews of their needs. This would be used by all HSS Trusts, Education and voluntary organisations in Northern Ireland.
- Each family should be allocated a member of staff who will act as the main point of contact for the family and the co-ordinator of service inputs.
- A 'service map' should be created for each individual child and family and shared with all services and persons who have an involvement with them. Names and contact details should be provided of all those included in the map.
- Each new HSS Trust should undertake an audit of nursing services for children with particular respect to future roles and functioning of children's community nursing; the interface it has with the acute sector and with other community nurses and their partnerships with the voluntary sector.
- Assured funding is needed for community children's nursing services and the provision of flexible, out-of-hours responses by nurses in the community.
- Joint planning with the Department of Education is required, notably on joint funding arrangements and having common healthcare assistant posts in schools.
- Accredited core training in specific procedures needs to be available regionally for nurses and healthcare assistants (e.g. provided by a peripatetic training team). This core training could then be individualised for specific children according to their needs. Opportunities should be given to parents to avail of this and other training.
- DHSSPS needs to instigate urgent reviews of the commissioning and delivery of equipment (e.g. hoists, frames) to children and families. This review must involve education. The recently commenced review of wheelchairs that is led by the SHSSB, should give specific attention to the needs of children.
- DHSSPS and the HSC Authority need to urgently review respite provision for children with special needs; particularly with respect to nurse involvement as this is deemed necessary for children with complex physical healthcare needs. This review should involve education.
- An increase is needed in local respite options for these children and families.

6. The DHSSPS and the HSC Authority will commission a review of respite provision for children throughout Northern Ireland.
7. A review of provision of equipment to children with complex physical healthcare needs will be undertaken. This will be done with reference to the ongoing review of wheelchair provision.

8. A regional Forum on nursing children with complex physical healthcare needs will be established to share good practice.
9. There will be regional commissioning of training for nurses and healthcare assistants.

In conclusion, an ambitious but attainable programme of work has been identified. Resolving some of the issues highlighted in this Report will probably bring benefits to other client groups and it may provide a 'test-bed' for new methods of co-ordinating the planning and delivery of services. The changes resulting from RPA offer a unique opportunity to develop innovative approaches; albeit ones that have proved useful beyond Northern Ireland as well as those that are particular to the local situation.

References

McConkey, R. & Adams, L. (2000) Matching short-break services for children with learning disabilities to family needs and preferences. *Child: care, health and development*, 26, 429-444.

McPherson, M. et al (1998) A new definition of children with special health care needs, *Pediatrics*, 102, 1, 137-140.

Merseyside and Cheshire Cancer Network (2004) Children's palliative care strategy, 2004-2006.

Regional Forum for Learning Disability in Northern Ireland (2007). The role of community nurses (learning disabilities) in working with children who have a learning disability.

SHSSB/SELB (2005) Summary Report of complex healthcare needs of children in schools.

Appendices

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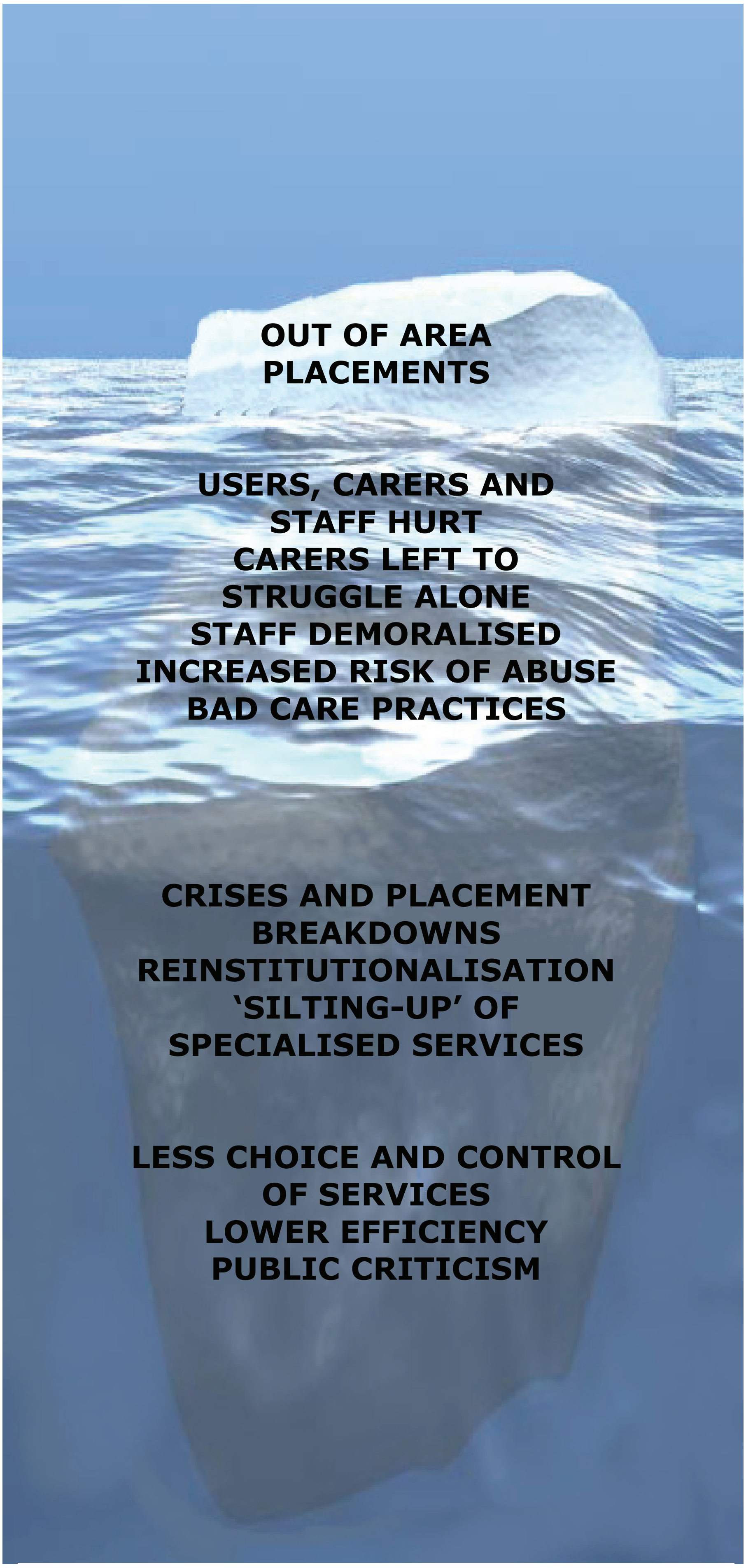
June 2007

SERVICES FOR PEOPLE WITH LEARNING DISABILITIES AND CHALLENGING BEHAVIOUR OR MENTAL HEALTH NEEDS

(REVISED EDITION)



The hidden cost of failing to develop local services

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Author	Department of Health		
Publication Date	October 2007		
Target Audience	PCT CEs, NHS Trust CEs, Care Trust CEs, Foundation Trust CEs , Directors of Nursing, Local Authority CEs, Directors of Adult SSs, Directors of Children's SSs, Directors of Commissioning		
Circulation List	SHA CEs, Directors of PH, Directors of Finance, Allied Health Professionals, GPs, Voluntary Organisations/NDPBs		
Description	In 1993, DH published 'Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs'. To update this, Professor Mansell's report aims to support commissioners in developing local services for people whose behaviour presents a significant challenge. The report makes recommendations on commissioning for service development and implementing models that meet individuals' needs in the local community.		
Cross Ref	Services for People with learning disabilities and Challenging Behaviour or Mental Health Needs (1993)		
Superseded Docs	N/A		
Action Required	N/A		
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Contact Details	Social Care Policy & Innovation 120 Wellington House 133-155 Waterloo Road London SE1 8UG SCPI-Enquiries@dh.gsi.gov.uk http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Learningdisabi		
For Recipient's Use			

SERVICES FOR PEOPLE WITH LEARNING DISABILITIES AND CHALLENGING BEHAVIOUR OR MENTAL HEALTH NEEDS: REPORT OF A PROJECT GROUP

(CHAIRMAN: PROF J L MANSELL)

Revised edition
October 2007

Contents

Ivan Lewis MP
Parliamentary Under Secretary of State for Care Services
Department of Health
Richmond House
79 Whitehall
London SW1A 2NS

9 March 2007

Dear Minister

I present the report *Services for people with learning disabilities and challenging behaviour or mental health needs,* which I have revised and brought up-to-date.

The analysis set out in the first version of this report and its recommendations remain relevant today. The goal of all services for people with learning disabilities should be to provide sufficiently skilful support to prevent problems arising in the first place, to manage them when they occur and to implement relatively sophisticated long-term arrangements for management, treatment and support. Specialised challenging behaviour services will then be able to focus on people who present the most complex and difficult challenges.

Although there has been good progress on many fronts since the publication of *Valuing People*, progress in respect of challenging behaviour has lagged behind. The failure to develop appropriate services has led to an increase in the use of placements which are expensive, away from the person's home and not necessarily of good quality.

The main reason for this is that commissioning has been too reactive and has therefore become dominated by trying to manage crises. What is needed is for Councils to strengthen their commissioning to combine expertise about challenging behaviour with the ability to actually develop services for individuals so that they are ready when needed. This is entirely consistent with the Government's focus on personalisation and prevention in social care.

Yours faithfully

(Prof) J L Mansell

Foreword from the Parliamentary Under Secretary for Care Services

Since the publication of *Valuing People* in 2001, progress has been made in a number of areas to improve the lives of people with learning disabilities. There are a great number of people committed to delivering its principles of rights, independence, choice and inclusion.

However, while good progress has been made, challenges still remain and this is perhaps particularly evident in making real changes for people with learning disabilities who are considered to have challenging behaviour.

We are finally reaching the end of the closure of the remaining old long-stay hospitals and are embarking on our programme of work to close all NHS residential accommodation or 'campuses' by the end of the decade. Real progress is being made in giving people back their independence and control and I am always delighted to hear people's stories of how their lives have changed for the better when they get back the control that we all have a right to. Person-centred planning is a vital component in delivering this independence and control, ensuring that in providing for a person's needs, that their wishes and aspirations for their own life form a central part of the plan.

Good quality commissioning and service provision is also vital in delivering that vision. There are positive examples from across the country demonstrating progressive thinking and innovative ideas. It is important that that knowledge and learning is shared and developed to the benefit of people with learning disabilities and those who work with them.

Valuing People clearly states that good quality services will ensure that people with additional and complex needs are appropriately cared for so that their needs are well managed and they lead fulfilling lives. It acknowledged that commissioning and providing services for people who present significant challenges is one of the major issues facing learning disability services. This revised and updated version of the report by Professor Jim Mansell and his project team will be invaluable in meeting that challenge. I encourage all those involved in services for people with learning disabilities and challenging behaviour or mental health needs to develop those services in line with the best practice set out in this report.

I am committed to reinvigorating the learning disability agenda and this good practice guidance supports us in that goal.

Ivan Lewis
Parliamentary Under Secretary of State for Care Services
October 2007

Preface

This report is issued as best practice guidance to councils with social services responsibilities and health bodies. It is not mandatory and no extra resources will be provided for its implementation. Councils and health bodies should take it into account in setting their own priorities and policies. It will also be useful to people using services, their families and representatives, staff and service-providing organisations as a statement of best practice.

Key recommendations

The following key recommendations are crucial to developing and sustaining quality services to meet local needs. These recommendations provide a means to plan strategically; to develop preventative strategies that avoid crises; and to make the most effective use of available funding.

Aims

1. Better use of investment is required to achieve two aims:
   - to develop and expand the capacity of local services for people with learning disabilities to understand and respond to challenging behaviour
   - to provide specialist services locally which can support good mainstream practice as well as directly serve a small number of people with the most challenging needs (paragraph 48).

2. Commissioners should give priority to improving services for people with learning disabilities whose behaviour presents challenges to services (paragraph 70). They should demonstrate value for money through improvements in the outcomes identified in *Valuing People* – rights, inclusion, independence and choice – as well as on the specific treatment of challenging behaviour (paragraph 73). At service system level, value for money should be demonstrated by a low number of placement breakdowns and of out-of-area placements (paragraphs 73 and 76). Low-value high-cost services should be replaced by better alternatives (paragraph 74).

3. Commissioners should avoid increasing the burden on family carers by reducing levels of service (paragraph 75).

Service models

4. Councils should re-examine the continued use of residential special schools away from people's homes in the light of identified problems, to explore the provision of local services which offer at least as good education and care (paragraph 24).

5. Commissioners should ensure that opportunities for short breaks tailored to individual needs are available to every family supporting a person whose behaviour presents a challenge at home (paragraph 49).

6. Direct payments and individual budgets should always be considered in planning for individuals and should be made more widely available (paragraphs 51 and 78).

7. Commissioners should stop using services which are too large to provide individualised support; serve people too far from their homes; and do not provide people with a good quality life in the home or as part of the local community, in favour of developing more individualised, local solutions which provide a good quality of life (paragraph 52).

8. Whether people are living in their family home or in accommodation with support, they should have access to innovative day opportunities (paragraph 54). Where people are excluded from day services because of their challenging behaviour,

commissioners should ensure that they provide alternative day services which can offer good services in spite of the challenges people present (paragraph 55). Supported access to further education should be available to everyone, alongside supported employment and other day opportunities (paragraph 56). Commissioners should take the lead in developing a much wider range of alternative models (paragraph 57).

9. Additional specialist multi-disciplinary support teams focused on challenging behaviour are an essential component of modern provision (paragraph 61). Specialist services need to use their skills to help managers in the provider network lead their staff in the provision of effective local services. This requires closer co-ordination between the commissioners paying for services, the managers providing services and the professional specialists advising on the support people need, to ensure that advice is both practicable and is acted upon. (paragraph 63).

10. Emergency support for people whose behaviour presents a challenge should be available 24 hours a day, seven days a week (paragraph 64).

11. The appropriate role for psychiatric hospital services for people with learning disabilities lies in short-term, highly focused assessment and treatment of mental illness. This implies a small service offering very specifically, closely defined, time-limited services. (paragraph 59)

12. Commissioners should allocate a budget to be used to fund a much wider variety of interventions as an alternative to placement in a special unit (paragraph 67).

Commissioning for service development

13. Learning Disability Partnership Boards should monitor that local agencies are working together to provide effective services for people whose behaviour presents a challenge to services and report when they are not. (paragraph 72).

14. Planning ahead is required for everyone. As a priority, councils should fund the independent advocacy and co-ordination required to ensure at least that every person whose behaviour presents serious challenges to services has a proper person-centred plan for the services they need now and in the coming years. Planning ahead also implies building in some capacity in the system to cope with demand as it emerges, rather than waiting until crises occur. (paragraph 82).

15. Councils should strengthen their commissioning to combine expertise about challenging behaviour with the ability to actually develop the services needed. This is required at both strategic and operational levels. At strategic level, Councils should
    - *Garner resources*: work with other relevant agencies to identify all current expenditure on learning disability, including resources accessed in emergency or crisis, and obtain agreements to pool these resources and to work together to improve outcomes for people whose behaviour presents a challenge.
    - *Audit provision*: find out which services are good at supporting people whose behaviour presents a challenge and which are not, and why.
    - *Assess need*: find out how many people have behaviour which presents a challenge, including

  - Young people approaching transition from school
  - People placed in the area funded by other authorities
  - People living at home not receiving services
  - People placed out-of-area
- ♦ *Develop partnerships*: work with provider organisations who are committed to developing good services to support people whose behaviour presents a challenge to agree commissioning and funding arrangements that will achieve value for money while sustaining investment and development in local services.
- ♦ *Plan services*: forecast the amount of new housing, day opportunities and support that will be required in the years ahead; map the staffing and staff training implications of this; and plan how this will be financed (paragraph 83).

16. At operational level, councils should
    - ♦ *Create service development resource*: identify people who know about challenging behaviour and services, to work with people to implement their person-centred plans. Such a team should combine aspects of commissioning and care management and work alongside professionals providing specialist support.
    - ♦ *Identify people as a first priority*: these should be people whose behaviour presents a serious challenge to services, focusing on those people where problems are serious enough that intervention could make an important difference but where the context is supportive enough to allow the greatest impact.
    - ♦ *Develop services*: support the person-centred planning process for these people and deploy resources to implement the plans developed.
    - ♦ *Provide back-up*: notice when problems being to emerge (before they reach crisis-point) and intervene to provide moral and material support to sustain arrangements through difficult periods.
    - ♦ *Extend development to more people*: as successful arrangements become established, take on the support of additional people (paragraph 84).

17. The role of the National Health Service is
    - ♦ To keep contributing the financial resources needed to sustain the transfer of specialist learning disability services to councils.
    - ♦ Not to undermine the strategy set out in this report by commissioning poor-quality services, especially out of area, themselves.
    - ♦ To continue to provide sufficient levels of the professional support required to sustain good practice in community based services.
    - ♦ To provide specialist psychiatric assessment and treatment on a short-term basis, but only as part of an integrated pathway of care for the individual that gets them back into the community.
    - ♦ To enable fair access to generic health (including mental health) services for people with learning disabilities whose behaviour presents a challenge to services (paragraph 86).

18. The Sector Skills Councils should support service development by recognising more specialised and advanced courses in challenging behaviour and specialised training at a more advanced level than NVQ2 should be a requirement where people present challenging behaviour (paragraph 92).

19. The Commission for Social Care Inspection, the Healthcare Commission and the Care Services Improvement Partnership (through the Valuing People Support Team) plan work which will help local authorities and health bodies to improve services for people with learning disabilities whose behaviour presents a challenge (paragraph 93).

Introduction

1. The first version of this report[1], published in 1993, provided guidance for councils and health bodies on the development of services for adults with learning disabilities whose behaviour or mental health problems present a challenge to services. The guidance was focused particularly on commissioners, because there was already ample information about service models available for providers. In 2001, the Government White Paper *Valuing People*[2] reaffirmed this guidance.

2. A great deal has changed since 1993. The old long-stay hospitals are nearly closed. Most people with learning disabilities – including most people who present challenging behaviour - live in the community either with their families, in small residential homes or in their own homes, with varying levels of support. The idea that services should be designed around the individual, relatively new in the first report, is now central to government policy in the 2006 White Paper *Our health, our care, our say*[3].

3. These changes have posed new problems for people with learning disabilities whose behaviour or mental health problems present challenges. Often, community-based services have not been sufficiently well-developed and well-organised to serve them. Placements break down as people whose behaviour presents a challenge can no longer be supported. For those who have been living with their families, there are insufficient local placements prepared to take them. For people already in supported accommodation or residential care, the placement is unable to cope[4]. For some individuals, this means they are required to move from one place to another over and over again, causing distress to them and their families.

4. The shortage of suitable local services is often remedied by finding placements outside the local area, sometimes a long way from home. There are over 11,000 people supported out of area by local authorities in England[5], 31% of all people with learning disabilities supported by local authorities. Challenging behaviour is a common reason for such placements, which can be very expensive[6-9] and the increasing number of such placements probably contributes to the dramatic rise in social services expenditure on learning disability services[10].

5. A third problem is that poor quality institutional services persist, either locally or in out-of-area placements. Sometimes these are assessment and treatment units, as in the recent inquiry in Cornwall[11]; a quarter of people placed in such units by primary care trusts have finished treatment[12] but presumably have nowhere to go. Institutional practice also exists in long-term placements in the community; these can be smaller-scale placements (such as supported living arrangements in Cornwall) but they are often larger settings where every resident has challenging behaviour[13]. There is some evidence that people placed out-of-area may experience worse services[7 14].

6. Thus, despite the progress that has been made for people with learning disabilities in general, there has been a failure to deliver the benefits of previous policy to people who present a challenge to services. These problems were foreseen in the first version of the report and the guidance it contained remains relevant now. This revised version

updates the report to reflect recent experience and changes in the organisation of social and health care. As before, the report is heavily based on evidence from research, but the revision was also informed by further discussions with families, services, commissioners and other experts.

7. The report focuses on people whose behaviour presents a significant challenge to services, whether mental illness is implicated or not. It includes people who are on the autistic spectrum and a learning disability. It applies to services for adults, except in so far as issues of the transition from children's to adult services are involved.

8. The phrase "challenging behaviour" is therefore used in this report to include people whose behaviour presents a significant challenge to services, whatever the presumed cause of the problem. Wherever it is used, it includes behaviour which is attributable to mental health problems. As a working definition, that proposed by Emerson *et al*[15] has been used

> "Severely challenging behaviour refers to behaviour 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 which is likely to seriously limit or delay access to and use of ordinary community facilities."

When the term 'challenging behaviour' was introduced, it was intended to emphasise that problems were often caused as much by the way in which a person was supported as by their own characteristics. In the ensuing years, there has been a drift towards using it as a label for people. This is not appropriate and the term is used in this report in the original sense.

9. One of the major changes since *Valuing People* is the recognition that all public services have responsibilities towards people with learning disabilities. Although this report focuses mainly on health and social services, other services are increasingly important. People with learning disabilities have the same rights to housing as other people, and housing providers need to support people who present challenges. Education services (particularly schools and further education colleges) are also important partners in serving people with learning disabilities whose behaviour presents a challenge. Ordinary health services too need to be able to serve people whose behaviour challenges. In all these areas, both statutory and independent sector services are involved. For example, social services are commissioned by local councils but largely provided by the independent sector; health services are commissioned by National Health Service bodies and provided both by the NHS and by independent health care providers.

10. The Reed Committee[16] produced guidance specific to people with learning disabilities classified as mentally disordered offenders. More recent advice for commissioners has been produced by the North West Regional Task Force on Learning Disability[17]. Further national guidance is provided by the Care Services Improvement Partnership[18] and by the Department of Health[19].

The people involved

Individuals themselves

The client group

11. People with learning disabilities whose behaviour presents a challenge form an extremely diverse group, including individuals with all levels of learning disability, many different sensory or physical impairments and presenting quite different kinds of challenges. The group includes, for example, people with mild or borderline learning disability who have been diagnosed as mentally ill and who enter the criminal justice system for crimes such as arson or sexual offences; as well as people with profound learning disability, often with sensory handicaps and other physical health problems, who injure themselves, for example by repeated head banging or eye-poking. Some brief illustrative examples of individual problems and service responses are given in Appendix 1.

The needs of individuals

12. People whose behaviour challenges have the same needs as anyone else, in addition to special needs for help to overcome the problems their behaviour presents. They do not surrender their needs for personal relationships, for growth and development or for anything else because their behaviour presents a challenge to services. They have the same human and civil rights as anyone else.

13. In considering individual need, the same attention to issues of race and gender as required in other services should apply. There is evidence from mental health services of different, more restrictive, treatment of service users from ethnic minorities. Similar problems may exist in services for people with learning disabilities. Women whose behaviour presents a challenge may also experience a different standard of service. In mixed-sex houses they may be more vulnerable to sexual harassment and assault; they may experience greater restrictions in the expression of their sexuality than men; and aggression by them may be interpreted as a greater challenge than the same behaviour from a man.

Factors contributing to challenging behaviour

14. Challenging behaviour is *socially constructed*; it is the product of individual and environmental factors interacting together. Individual factors are the characteristics people bring with them – the severity of their learning disability, the presence of additional sensory or motor disabilities, mental health problems, communication difficulties, their personal history of relationships and experiences and so on. Environmental factors are the characteristics of services – the number, training and experience of staff, how they work with the people they serve and with each other, the quality of the material environment and the opportunities it presents.

15. Where individuals with problems are cared for in environments which do not respond well to their needs, challenging behaviour is likely to develop and then to remain in the person’s repertoire. The individual risk factors (such as communication difficulties or a history of abuse) are quite widespread among people with learning disabilities: for example, between 10 and 46% of adults have additional mental health

needs[20]; 12-15% have significant impairment of sight[21], 8-20% of hearing[22], 27% have autistic spectrum disorders[23] and at least 45% have significant impairments of communication[24]. Environmental risk factors (such as poorly organised and trained staff) are widespread among services. The dominant model of support in services for people with learning disabilities is relatively unskilled caring and 'minding'. The evidence is that staff do not generally interact with the people they support in a way that enables them to achieve greater levels of independence, participation or integration. The amount of support received is relatively low (about 9 minutes in every hour) and facilitative assistance much less (1-4 minutes an hour on average)[25 26]. Front-line staff often overestimate the receptive language ability of the people they support[27]. Psychological treatment for challenging behaviour remains difficult to get[28]. There is substantial turnover of staff with the associated difficulties of recruitment and training[29]. The potential for challenging behaviour arising and becoming more severe is therefore greater among less well organised services.

16. In general, transfer from institutional to community services (ie the provision of enriched environmental, physical and social circumstances) has not reduced challenging behaviour or mental health problems[25 30-32] - and given the functions served by some challenging behaviour, there are good reasons to expect increases in some cases[33]. It is not therefore simply a matter of switching the service model and expecting the problem to disappear.

17. Neither is it usually possible to treat and cure challenging behaviour. Biomedical intervention is only effective where there is an underlying mental health problem which has been correctly diagnosed. The use of anti-psychotic medication as a means of behaviour control may mask the problem but does not cure it[34 35]. Psychological treatments have the strongest empirical support[36]. However, even where staff are sufficiently well-organised to undertake psychological treatment of challenging behaviour, the results are often short-lived. One reason for this is the difficulty staff often have of maintaining appropriate levels of organisation and skill in their interaction with the service user over time[37]. Once challenging behaviour has become useful for the person, it remains as an option in the individual's repertoire to appear again whenever alternatives cease to be as effective[38].

18. None of this is to deny that effective intervention can make a difference. Of course services should aim to help people overcome their challenging behaviour, and there are many examples of how this is being achieved. The point is that good practice is fragile, and it is not sensible to plan on the basis that challenging behaviour can be readily 'fixed.' Thus, the potential for challenging behaviour exists for many service users in many situations; and the problem of challenging behaviour is not likely to go away. The implication is, therefore, that the appropriate goal of learning disability services is to support the individual in achieving as good a quality of life as possible *in spite of* their problems. In practice, challenging behaviour will be an enduring characteristic of the lives of many service users. There will always be a large pool of people who present some challenging behaviour, which can be better or worse depending on how well services support them.

19. A proportion of this 'at risk' population at any one time present an exceptional challenge to services because of their behaviour. Estimates depend on definitions, but over the whole country it is likely that about 24 adults with a learning disability per 100,000 total

population present a serious challenge at one time[39]. This means that there are over 12,000 people with learning disabilities in England whose behaviour presents a serious challenge at one time. This includes people with mild as well as severe learning disability. A few of these people will present such a challenge more or less all the time and will become well-known to local services (as well as, in some cases, other agencies like the police and housing departments); but many people will move into and out of this group depending both on changes in their characteristics and on how well services meet their needs over time.

Implications for services

20. The implications of the nature of challenging behaviour for services are that

- service planning and delivery should be highly individualised, to meet the widely differing needs of people in this group
- the special help that services provide in response to challenging behaviour should be in addition to, not instead of, the same standard of service to meet the needs that people whose behaviour presents a challenge have in common with others
- services should be planned on the basis of accurate information about individuals, rather than on the basis of norms, since needs vary so much and depend on service capability
- services should be designed and provided to reflect available research evidence about best practice, since poor quality services are likely to be ineffective even if expensive
- the reduction of challenging behaviour is likely to require attention to other factors (such as communication) than just the behaviour itself
- assessing need should involve assessing service competence as much as individual characteristics
- preventing the development and worsening of challenging behaviour is a priority because of the costs (to the individual, family and society) of problems escalating or becoming ingrained
- maintaining local links by providing local services is also a priority because once people are placed far away it is difficult to organise their return and expensive to support them

The needs of family carers and staff

21. Services exist to meet the needs of their users; but, within this framework, the needs of carers should also be considered to be very important, both because services cannot succeed without the contribution made by carers and because as a matter of principle one group of people's needs should not be met at the expense of another. Of course there will be important conflicts of interest between service users and their carers which will need to be faced up to at an individual level. But services should not be provided by exploiting the personal commitment and dedication of carers.

22. Families who care for individuals whose behaviour presents challenges are subject to considerable and continual stress, both physical and psychological. Although staff are not permanently on duty as family carers can be, they are still subject to the same stresses when supporting people whose behaviour challenges. This is true even in settings which aim to do no more than contain people. Similar concerns apply to staff as to carers. The higher aspirations often found in progressive services impose extra

strain on staff and here too it is important to balance the demands of working constructively with people who can be very difficult, day in and day out, with the needs of individual staff for emotional and practical respite and ongoing support.

Additional pressures on services

23. Demographic changes and rising expectations will increase the demand for accommodation with support for adults with learning disabilities[40]. Increased numbers of people with specific conditions (especially autistic spectrum disorders) is already placing extra demands on services. The tightening of eligibility criteria for social services has led to a larger number of people staying in their family home well into adult life[41] and to reductions in opportunities for short breaks for families supporting people with profound learning disabilities[42 43]. Since challenging behaviour is one of the common reasons why people need to leave the family home, pressure on families to manage without these options is also likely to be increasing. This is unlikely to be in the best interests of either the disabled person or their family, and may end in crisis.

24. Challenging behaviour is often implicated in the placement of children with learning disabilities in residential special schools[44 45]. These placements are often disruptive of ties with family and community, so that families face particular problems getting local services which can provide the level of support needed when responsibility passes from children's to adult services[46 47]. The continued use of residential special schools away from people's homes needs to be re-examined in the light of these problems, to explore the provision of local services which offer at least as good education and care.

25. There has been an increased focus on the management of risks to health and safety in social and health services, including 'zero-tolerance' for violence against staff[48]. Where inappropriately applied, these initiatives can lead to people with learning disabilities who may present challenging behaviour being denied opportunities to live their lives, in order to avoid risks to individuals and to organisations. It is important that such risks are appropriately managed, balancing the risks of challenging behaviour against the risks of reduced quality of life. It is not an appropriate or achievable goal that the risk of challenging behaviour be completely eliminated.

Characteristics of exemplary services

26. The first version of this report was based on the experience of four exemplary services. All were specialist services designed to support learning disability services to support people whose behaviour presents a challenge. The Additional Support Team, Exeter[49] provided specialist advice, extra help in community settings and some backup provision in the form of specialised small staffed houses for people whose behaviour presents a challenge (used mainly by people with mild learning disabilities). The Special Projects Team, Sunderland[50] was based on a team of skilled community support workers, supplemented by a six-place alternative day service and a specialised staffed house in the community; it focused on people whose learning disability (rather than mental health) was the primary problem. The Mental Impairment Evaluation and Treatment Service[51-58] was a hospital-based assessment and treatment service for people with mild learning disabilities, the majority of whom had criminal convictions and additional mental health needs. The Special Development Team[59 60] provided advice and help to enable local services to establish housing placements for people with severe or profound learning disabilities who presented challenging behaviour.

27. Since cost is sometimes given as a reason why adequate services for this group of people are not developed, it is worth noting at the outset that these services were all developed within the existing resource framework available to their host agencies. Resources are a question of priorities as well as of the amount available. It is also worth noting that the available evidence suggests that the small-scale residential services involved are not more expensive than higher priced institutional placements. They are more expensive than low-staffed hospitals or private homes, but the research suggests that the outcomes achieved in low-staffed services are much poorer[59].

28. The extent to which exemplary services have been successful depends on a number of factors discussed below. These are grouped under five headings: commitment, individualisation, effective models of care, good management and investment in relationships. No-one involved in such services would claim that they are perfect: but their experience does illustrate some of the issues which must be attended to if services are to meet the needs of people who have challenging behaviour.

Commitment

29. Successful services have typically been built up by a committed group of professional and front-line staff, working with the sustained support of senior policy-makers and managers. As in many innovations, they have tended to work outside existing structures and relationships and this has enabled them to develop new ways of working which have had considerable success.

30. A key observation made to the Committee[*] was that the senior managers of local service agencies could be classified by their intentions in relation to services for people whose behaviour presents a challenge, and that this helped explain different approaches to service development for this client group.

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[*] By George Gaskell and Julie Dockrell of the London School of Economics; the classification presented here is a modified version of that they proposed.

- ‘Removers’ do not want to develop locally the competence to serve people whose behaviour presents a challenge (perhaps because they perceive the task as too difficult, or not worth the effort). They seek instead to place people who cannot be served locally in out-of-area residential placements, often at considerable expense.
- ‘Containers’ do seek to provide local services (perhaps because of the cost of out-of-area placements) but seek only to contain people in low-cost (and therefore poorly-staffed) settings.
- ‘Developers’ seek to provide local services which really do address individual needs, and therefore give higher priority to funding services which, with more staff and more training and management input, are more expensive than ordinary community services.

31. The knowledge and skills needed to develop effective local services are increasingly widely available; it is the extent to which policy-makers and senior managers want to do this which may be the key limiting factor.

Individualisation

32. Successful services are individualised, in a number of ways. First, they recognise that individuals need to experience well-coordinated services, committed to meeting their complex needs over the long term: so they tend to ignore professional or organisational boundaries, trying to construct packages of care that meet individual needs rather than making people fit into existing services; and they ‘stick with’ individuals in spite of the difficulties experienced in meeting their needs.

33. Secondly, the way packages of care are constructed really is based on thoroughly knowing and understanding the individual and their experience. Partly this is done through sophisticated assessment of different kinds (for example, functional assessment or detailed assessments of communication), but more than this staff get to know the individuals and their backgrounds well. The current framework for doing this is person-centred planning[61].

34. Coupled with individualised planning and operation of the services received by an individual, costs are represented, and the case for resources made, at an individual level. Services are therefore in a much better position to demonstrate the value for money they achieve for individuals than services set up for notional client groups or in response to norms or categories of people.

35. This approach is entirely consistent with the Government’s focus on personalisation. Of course individualised approaches are often difficult to arrange (for example where day care is organised on a ‘take it or leave it’ basis in large, poorly-staffed centres, or where general psychiatric services operate a blanket exclusion on treating people with learning disabilities). For social care services, direct payments[62] [63], the ‘In control’ project[64] [65] and individualised budgets[3] are all important mechanisms to help people organise services that provide what they need, when they need it. They will need to be complemented by a new approach to commissioning which promotes and sustains the new kinds of services people will need whatever mechanism they use to get them[66]. Individualised approaches are also promoted by specific legal obligations to provide

services (eg aftercare) and a growing emphasis in law on human rights and freedom from discrimination on the grounds of disability.

Effective service characteristics

36. Specialised services should have a clearly defined role. As extra resources, they offer specific services in support of mainstream local services for people with learning disabilities. In contrast to some institutional services which seemed willing to take anyone and unconvinced that any other agencies could possibly cope, modern services focus on a limited range of functions and are explicitly concerned to improve the capacity of local services to manage well. So, for example, services should not provide respite for people in crisis alongside a home for life.

37. Within this framework, the care and treatment offered to individuals is based on clearly stated assumptions and beliefs about what causes the individual's problem behaviour and what the service needs to do to prevent it, to manage it when it does occur, to treat it over the longer term and to stop it interfering with the quality of life of the individual concerned and those around them. Decisions about these issues are made in a genuinely multi-disciplinary context. This approach extends to all areas of the person's life and all relevant disciplines. It is in contrast to services which offer a general regime into which people are expected to fit irrespective of the different reasons they present a challenge. Guidance on these issues has been produced jointly by the Royal College of Psychiatrists, the British Psychological Society and the Royal College of Speech and Language Therapists[34].

38. Coupled closely with this is an emphasis on collecting and using good quality information both in assessment and to maintain a high standard of ongoing support to the individual. Good services focus on outcomes for the individual - independence, inclusion, choice and rights. They attend both to the challenge the person presents and to supporting the person to achieve a good quality of life in spite of their problems.

Good management

39. Services which have high aspirations need good management if their goals are to be realised in practice.

40. First-line and middle managers of the staff providing direct care need good understanding of the reasons for an individual's challenging behaviour and of how this interacts with the everyday organisation of the service. Thus, for example, someone learning greater self-control needs consistent feedback from different staff; a person who cannot tolerate complex spoken commands needs staff to monitor the way they approach them in line with a clear plan. This requires a greater degree of skill among staff and particularly good management (especially first-line management) to keep the service on track. Management is also crucial in ensuring that professional specialists and front-line staff work together; that specialist advice is available, practicable and sensible and that staff follow it.

41. In particular, managers need to distinguish the middle ground between pessimism about models of care ('you can't do anything with these people') and naive misinterpretations about normalisation ('only values matter - all structure is oppressive'); life for people with major disabilities supported by good services will

often look quite ordinary, but this ordinariness will be the product of a great deal of careful planning and management.

42. Since virtually all services claim to provide individualised care based on the latest assessment methods it is essential that service managers, commissioners and regulators can really discriminate between good and mediocre performance. This can be a particular problem for services providing long-term residential or day care, where a successful service looks like an ordinary home or occupation, when in fact it is a carefully designed and organised service dependent on a great deal of skill and management. It is important therefore to look directly at the lives of the people served (how they spend their time, how much help they get from staff, what relationships they have and so on) and not just to rely on the statements and beliefs the service has about itself.

Investment in relationships and networking

43. The last group of defining characteristics of examples of good practice is that they pay particular attention to the relationships between the service, the users, their families and the staff involved.

44. For individual service users, a history of challenging behaviour is also often a history of discontinuity in relationships and of bad experiences in relating to other people. Good services all make particular efforts to involve individuals in their care, to use advocates and to involve family members in person-centred planning.

45. These services also invest heavily in training for the direct care staff of the service. Most of this is specially designed in-service training, reflecting some dissatisfaction with the very limited competence in work with people who have challenging behaviour produced by traditional professional training and also emphasising the importance of training all staff, and training them all together as a team. Training includes not only understanding and responding to challenging behaviour but also the organisation of support in the person's home, day or leisure activity to provide good quality care in spite of a person's problem behaviour and in ways which minimise its likelihood and severity.

46. Each service also emphasises technical (ie about care and treatment) and emotional support for these staff. Technical support is largely provided from professional staff. The scarcity of some categories of staff (eg clinical psychologists, speech and language therapists) presents an obstacle to wider service development, particularly given the specialised nature of the expertise required. Emotional support, in recognition of the heavy demands that working with people who present very serious challenging behaviour make on staff, is equally important. Good team working, supervision, debriefing and counselling are important. Making good use of this support is also obviously dependent on achieving genuinely multi-disciplinary working.

Service models

47. Most people with learning disabilities whose behaviour presents a challenge to services are already living in the community receiving support from ordinary learning disability services. Those who are not could be, given the right kind of support. Effective support does not require different kinds of service but it does require more skilled staff support that is well organised to meet the person's individual needs.

48. Investment is required to achieve two aims:
    - to develop and expand the capacity of local services for people with learning disabilities to understand and respond to challenging behaviour
    - to provide specialist services locally which can support good mainstream practice as well as directly serve a small number of people with the most challenging needs.

Thus in practice a local service would include

- a range of small-scale housing, work, education and other day placements into which markedly different levels of staff support could be provided on the basis of individual need at a particular time
- a sufficiently skilled workforce to reduce the probability of challenging behaviour emerging or worsening throughout the service, and to provide a pool of sufficient skill to help services work through difficult periods
- skilled professional advice from a full range of specialists, working in a coordinated and genuinely multi-disciplinary way, and backed-up by good access to generic services (including mental health services)
- management commitment to and focus on service quality and the staff training and support to achieve this.

Supporting people living with their family

49. People with learning disabilities who have challenging behaviour living at home with their families need two main kinds of service at home:
    - Practical support. This may include equipment (for example adequate continence materials where the individual uses more than average because of their challenging behaviour), advice and training for family members in how to understand, interpret and manage situations the person finds challenging and staff support to work with the individual and give the rest of the family time to themselves. The results of giving families resources to organise their own support, through self-directed services such as 'In control', seem to be much better than those achieved by traditional home care services provided to older people[65 67].
    - Short breaks to give the person and their family time away from each other. A particular problem for people with learning disabilities who present challenges is that, although their needs for a short break may be very high, local authorities may discriminate against them because traditional local respite services find it hard to provide the support required. They may therefore be excluded from short breaks. Commissioners should ensure that opportunities for short breaks tailored to individual needs are available to every family supporting a person whose behaviour presents a challenge at home.

Supporting people in other accommodation

50. Members of the Committee were persuaded that the best model of residential service was likely to be support to enable people to live in ordinary housing. The available research evidence showed consistently poor quality of life in hospital (whether old or new campus-style hospitals); on other large-group models of care there is little quantitative research but since they share many of the resource and organisational characteristics of hospitals there are no grounds for believing they will achieve very different results. Research since 1993 has confirmed this judgment. Decisions will of course need to be made on the basis of what is best for each individual; but for most people supporting them in a home (their own home or a small residential home) near their family and friends will be the right decision. An important development since the first version of this report has been the recognition of housing rights, so that once people have a proper home they cannot just be moved from one place to another because services have difficulty providing the support they need.

51. Direct payments and individual budgets provide important new opportunities to provide housing and support in a way that is tailored to the individual needs of the person whose behaviour presents a challenge. These options should always be considered in planning for individuals.

52. The growth of residential homes which specialise in supporting people whose behaviour presents a challenge has not always brought the benefits which research and demonstration projects have shown can be achieved. Some of these services are too large to provide individualised support; serve people too far from their homes; and do not provide people with a good quality life in the home or as part of the local community. Commissioners should stop using such services in favour of developing more individualised, local solutions which provide a good quality of life.

53. Although the quality of community-based services varies widely, the factors that make for good services are relatively well-understood and there are many examples of good practice. The key to the difference between good and indifferent community services lies not in resources, but in the quality of management (especially first-line management).

Education, work and day opportunities

54. Studies of large-scale development of community services for people with learning disabilities in the United States show that the availability of a day service is associated with successful community placement for people whose behaviour presents a challenge[68]. Whether people are living in their family home or in accommodation with support, they should have access to day opportunities.

55. Traditional day centres have limited experience of serving people whose behaviour presents a challenge and, given relatively low staffing ratios, the limited curriculum and the use of large groups these services are in any case likely to face considerable difficulty. In contrast, small-scale alternative day services providing supported employment or innovative leisure or educational pursuits, seem to offer particular promise. This is consistent with the Government's agenda to modernise day services and people whose behaviour presents a challenge are likely to benefit particularly from this programme. Commissioners should therefore purchase day care in these

kinds of services, rather than in large day centres. Where people are excluded from day services because of their challenging behaviour, commissioners should ensure that they provide alternative day services which can offer good services in spite of the challenges people present.

56. People whose behaviour challenges have the same right to continued education as anyone else. Supported access to further education is an important opportunity which should be available to everyone, alongside supported employment and other day opportunities.

57. These different options may not be available in each area. If commissioners only purchase services that exist they are likely to perpetuate traditional models. They should therefore take the lead in developing a much wider range of alternative models.

Access to other health and social services

58. *Valuing People* set out a clear framework for people with learning disabilities, including people whose behaviour presents a challenge, using health and social services available to the whole community. It said that the government will ensure that people with learning disabilities have the same right of access to mainstream health services as the rest of the population; that health facilitators will be appointed from each local community learning disability team to support people with learning disabilities in getting the health care they need; that all people with learning disabilities are registered with a family doctor and have their own Health Action Plan.

59. In respect of mental health services, it is important that services available to the whole community increase their ability to meet the needs of people with learning disabilities whose behaviour presents challenges and who have a diagnosed mental illness. Making services responsive to the needs of these people is part of making them more personalised and capable of meeting the needs of all parts of society. Within this overall framework, some specialised mental health provision may be needed. The appropriate role for psychiatric hospital services for people with learning disabilities, where these will have a continuing existence, lies in short-term, highly focused assessment and treatment of mental illness. This implies a small service offering very specifically defined, time-limited services. The Department of Health intend shortly to issue guidance on specialist health services for people with learning disabilities.

Specialist support to services

60. The first line of specialist support to people with learning disabilities living with their families, or supported in their own homes or in residential care, is the community learning disability team. This should provide social work, psychiatry, psychology, speech and language therapy, physiotherapy, nursing (and sometimes other relevant disciplines).

61. Improving ordinary learning disability services so that they can better support people whose behaviour challenges is not a substitute for proper specialist services. In many areas, additional specialist multi-disciplinary support teams focused on challenging behaviour have been developed, recognising that the intensity and complexity of help required may be more than community learning disability teams can provide. Such

services are an essential component of modern provision. Basing their approach on recent research and development, such teams expect to analyse the challenging behaviour in the situation in which it is occurring and develop a package of intervention components which include 'ecological manipulation' (managing the situation to avoid triggering challenging behaviour while still supporting people to engage in meaningful activity and relationships), 'positive programming' (helping the individual learn functionally equivalent alternatives to challenging behaviour to get what they need), 'direct treatment' (responding to the challenging behaviour in a way that will reduce its functional effectiveness) and 'reactive management' (how to work with the person safely during episodes of challenging behaviour)[69]. This kind of approach requires careful, consistent, sustained implementation by staff, often over many days or weeks. They will need to work together as a team, to understand the principles underlying the professionals' prescription so that they can sensibly adapt to changing circumstances, to manage their interaction with the individual and keep careful record of events and incidents.

62. Given the level of training, turnover and the prevailing ethos in some services staff are not always able to respond to these demands. A common reaction is therefore a kind of stand-off. Staff providing direct support to people with learning disabilities say that professionals do not understand the practical constraints they face and generate action plans that are impossible to implement. Professionals report that staff are simply not able to carry out the necessary assessments and intervention[70]. They may lower their expectations but thereby risk plans being ineffective.

63. The way forward is that specialist services need to use their skills to help managers in service-providing organisations shape up the skill and quality of the service they provide. This requires closer co-ordination between the commissioners paying for services, the managers providing services and the professional specialists advising on the support people need, to ensure that advice is both practicable and is acted upon.

64. Given the importance of avoiding poor placement decisions made in a crisis, emergency support for people whose behaviour presents a challenge should be available 24 hours a day, seven days a week. Services that only work 'office hours' or which have waiting lists for support will not be able to provide an effective service to the individuals concerned, their families or the paid staff who support them.

65. When crises do occur, instead of the single solution of admission to a 'challenging behaviour unit', there needs to be a pool of staff and money which can be used more imaginatively to meet the particular needs of the situation. Special units fulfil a range of roles:

- Short breaks: to give the individual person using services a break from a difficult situation, or to give other residents or family a break from the person
- Intervention: to try out new way of working with the individual in a safer situation, to carry out biomedical investigation or to provide a high level of observation
- Breathing space: to provide a 'holding area' while a new placement is found

Fulfilling these different roles in the same setting is difficult. If the unit is a long way from the person's home, transferring any benefits of assessment and treatment may be impracticable[71] [72].

66. The difficulty of bringing people back home once they have been placed a long way away is so great that every effort should be made to avoid such placement. What is needed is a much wider range of options locally so that the individual needs of the person in crisis can be better met. For example, options for respite can be expanded by

- funding a short hotel break for the individual or those they live with
- providing more help at home
- staying with staff identified as having a particularly good relationship and skills with the individual
- spending less time in the house during the day
- using a local house or flat before it is permanently occupied
- staying in a designated short break care service

Options for intervention can be expanded by

- Extra skilled leadership/support for staff ('getting back on track')
- Extra skilled staff ('extra pairs of hands' or 'new pairs of eyes')
- Telesupport; phone or visiting checks
- Extra help to enable access to ordinary settings
- Stay in a designated assessment and treatment unit

Options for a breathing space can include

- Having services available for the individual when needed through proper person-centred planning
- Staying with staff identified as having a particularly good relationship and skills with the individual while a new property is found
- Turning property designated to provide individualised short break care into someone's home (and developing new short break places)
- Having spare capacity in anticipation of growth

67. Allocating a budget to be used to fund a much wider variety of interventions than placement in a special unit, often expensive and a long way away, would represent good value for money and good preventative action by commissioners.

68. All these elements of good practice are well understood and have been used to support people whose behaviour presents a challenge. However, they are not widespread in services. The central challenge is for commissioners to direct their investment to develop good practice, instead of continuing to fund services which, while they may solve some problems in the short-term, do not contribute to long-term solutions.

Commissioning

69. Combining the different elements of services to ensure that people with learning disabilities whose behaviour presents a challenge are served well is the job of commissioning. Models of good practice have been demonstrated and service providing organisations committed to good practice exist. However, in the period since 1993 development has not kept pace with need. Placement breakdown continues to be a widespread problem in community services; people are excluded from services; assessment and treatment facilities cannot move people back to their own home; some of the placements eventually found are low value and high cost. What is it that commissioners need to do to tackle these problems?

Commitment

70. The Cornwall Inquiry traced the abuse of people with learning disabilities, including people whose behaviour presents a challenge, to lack of focus and commitment by commissioners[11]. It is therefore worth restating the reasons why commissioners should give priority to these services:

♦ *These individuals have the greatest needs for services*. People with learning disabilities and challenging behaviour present the most complex and difficult problems, both at individual and service organisation levels. Although their numbers may be relatively small, unless services respond well they occupy disproportionate amounts of time and money.

♦ *Quality services achieve marked improvement*. Current research suggests that good quality services already make a substantial difference to the quality of life of individuals whose behaviour presents a challenge, and therefore by implication to their carers and staff. If the characteristics that make these services work were more widespread and better supported by management it would be possible to apply even more of the available knowledge at the individual level and to achieve even better results for individuals.

♦ *Failure to develop local services threatens the policy of community care*. Doing nothing locally is not an option. Out-of-area placements will `silt up' and reinstitutionalisation (through emergency admissions to psychiatric hospitals or via the prisons) will occur. Special institutions and residential homes for people whose behaviour presents a challenge will be expensive but of poor quality and will attract public criticism. Overall, the efficiency of services will decrease because of the widespread lack of competence in working with people who have challenging behaviour. Commissioners will have less control over and choice of services. Individuals, carers and staff will be hurt and some individuals whose behaviour presents a challenge will be at increased risk of abuse. Staff will be at increased risk from the consequences of developing their own strategies and responses and managers will be held accountable where well-intentioned staff operate illegal, dangerous or inappropriate procedures.

Agency responsibility

71. The development of joint commissioning between health and social services has removed some barriers and in many areas there is a record of health and social services, and to some extent housing, working together to make decisions about services for individuals whose behaviour presents a challenge.

72. However it is clear that problems remain, particularly in

- the perception that there is unilateral withdrawal of Primary Care Trust finance from joint initiatives when there are financial pressures elsewhere in the health service
- the reduction of Supporting People finance for individuals with relatively high needs for support
- the continued use of residential special schools a long way from home for children given the importance of maintaining local links for services in adult life.

The government is taking steps to improve the co-ordination of policy between the Department of Health, the Department for Education and Skills and the Department for Communities and Local Government to ensure that people with learning disabilities whose behaviour challenges are not disadvantaged. One of the key roles of Learning Disability Partnership Boards is to monitor that local agencies are working together and to report when they are not.

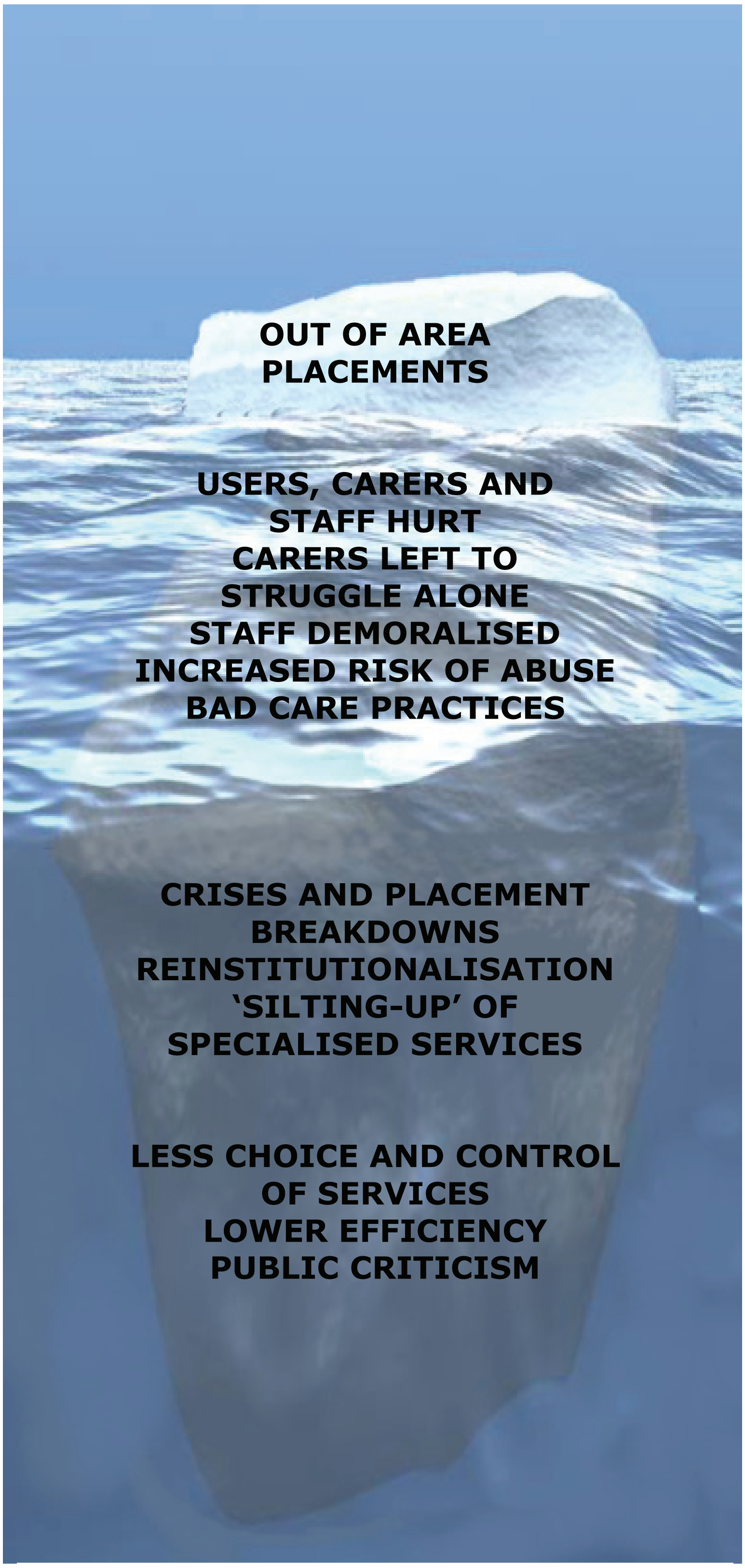
Value for money

73. All public services are required to demonstrate value for money. This does not mean providing services at the lowest possible price. Value for money requires a judgement about the benefits and outcomes produced as well as the costs incurred. In the context of challenging behaviour, commissioners should focus on the outcomes identified in *Valuing People* – rights, inclusion, independence and choice – as well as on the specific treatment of challenging behaviour. Commissioners should also consider adopting a Charter for people with learning disabilities who have challenging behaviour such as that in Appendix 2. At service system level, value for money needs to be demonstrated by the low number of placement breakdowns and of out-of-area placements.

74. Given that many services performing quite differently use the same language and make the same claims it is particularly important that commissioners are able to distinguish good outcomes from window-dressing. In particular, careful scrutiny is required of expensive services which appear to provide containment rather than a good quality of life: such low-value high-cost services should be replaced by better alternatives.

75. In considering costs, commissioners should take account of the hidden costs of failure to develop local services, such as the costs of handling crises and placement breakdowns (Figure 1). They should also pay attention to the financial and other costs borne by carers and should avoid increasing the burden on carers by reducing levels of service. As one parent said

> “They never think about the costs of not doing it”



The hidden cost of failing to develop local services

Figure 1

76. Commissioners should individualise costs to remove the confounding effect of averaging across clients and settings. In the short-term, they should certainly look to redirect resources from relatively expensive out-of-area placements to local service development, although it is clear that a very small number of individuals will be very expensive to serve wherever they live and it would be naive to expect cost savings as a matter of course. Such transfers will also incur the development costs of new placements and the transitional costs of replacing out-of-area with local provision. These cannot be avoided if the job is to be done properly.

77. They should also take care to identify all the current expenditure. It may be that adequate services for people whose behaviour presents a challenge will take more resources than currently allocated (since there is no logical basis to existing resource levels) but there are probably more resources in use than is apparent at first. For example some agencies spend substantial amounts of contingency reserves held at agency level on this group, while failing for want of money to develop the local capacity to serve.

78. It is already clear that most people using self-directed services find they provide much more value for similar costs[65]. Making this option available to more people with learning disabilities whose behaviour presents a challenge is therefore important.

Service development

79. Current commissioning practice is too reactive. The problems are summed up in this mother's account of her family's struggle to get services for her son:

> "At a fairly early stage, it was recognised that he was difficult. No one knew quite what to do. Education just wanted to put him somewhere at minimal cost. They took ages to go through bureaucratic processes - either complete incompetence or delaying tactics. Eventually they agreed a residential school placement and told me to find somewhere. Once he was there [over 250 miles away], they had no interest, sending a representative maybe three times in 10 years. When he was 15 I wrote to social services to tell them about him and ask them to plan for his return. They wrote back and said he was not their responsibility until he was 18. The default position was to find a residential home somewhere willing to take him. Setting up a new local service to meet his needs was not an option. The reasons for the lack of local service development are that it is too complicated, there is no set-up funding, no one to take responsibility for leading it - care managers know there is a need, but can't make it happen. Separate children's and adult teams are not helpful; children's team don't have responsibility beyond 18/19, so don't plan; adult teams are already overworked, so don't want to take responsibility before they have to. There is a culture of crisis management and a lack of creative thought. This all seems very negative but there are some good people trying to change things - but the odds are stacked against them. There is no strategic plan – it is all haphazard and disjointed."

80. At present, in many localities, too few service providers can support people with moderate to severe challenging behaviour well. Many commissioners have typically purchased services on the basis of lowest cost in the short-term, without considering the

long-term effects when things go wrong. Instead they need to work with service providers who are committed to developing the capability to serve people well in spite of their challenging behaviour and who can provide services locally. This will entail long-term partnerships between commissioners and service providing organisations.

81. This will mean proper planning for individuals well ahead of them needing services. The Government has emphasised the importance of transition planning and has promoted a new project to help councils use person-centred planning in the transition process[73]. Nowhere is this more important than in the service of people whose behaviour presents a challenge. It is inexcusable that councils, responsible for provision of services to both children and adults, should not have well coordinated transition planning arrangements.

82. Planning ahead is required for everyone. As a priority, councils should fund the independent advocacy and co-ordination required to ensure at least that every person whose behaviour presents serious challenges to services has a proper person-centred plan for the services they need now and in the coming years. Planning ahead also implies building in some capacity in the system to cope with demand as it emerges, rather than waiting until crises occur.

83. Person-centred plans need to be translated into action. Councils should therefore strengthen their commissioning to combine expertise about challenging behaviour with the ability to actually develop the services needed. This is required at both strategic and operational levels. At strategic level, Councils should

- ♦ *Garner resources*: work with other relevant agencies to identify all current expenditure on learning disability, including resources accessed in emergency or crisis, and obtain agreements to pool these resources and to work together to improve outcomes for people whose behaviour presents a challenge.
- ♦ *Audit provision*: find out which services are good at supporting people whose behaviour presents a challenge and which are not, and why.
- ♦ *Assess need*: find out how many people have behaviour which presents a challenge, including
  - Young people approaching transition from school
  - People placed in the area funded by other authorities
  - People living at home not receiving services
  - People placed out-of-area
- ♦ *Develop partnerships*: work with provider organisations who are committed to developing good services to support people whose behaviour presents a challenge to agree commissioning and funding arrangements that will achieve value for money while sustaining investment and development in local services.
- ♦ *Plan services*: forecast the amount of new housing, day opportunities and support that will be required in the years ahead; map the staffing and staff training implications of this; and plan how this will be financed.

84. At operational level, councils should

- ♦ *Create service development resource*: identify people who know about challenging behaviour and services, to work with people to implement their person-centred plans. Such a team should combine aspects of commissioning and care management and work alongside professionals providing specialist support.

- *Identify people as a first priority*: these should be people whose behaviour presents a serious challenge to services, focusing on those people where problems are serious enough that intervention could make an important difference but where the context is supportive enough to allow the greatest impact.
- *Develop services*: support the person-centred planning process for these people and deploy resources to implement the plans developed.
- *Provide back-up*: notice when problems being to emerge (before they reach crisis-point) and intervene to provide moral and material support to sustain arrangements through difficult periods.
- *Extend development to more people*: as successful arrangements become established, take on the support of additional people.

85. Recognising the fragmented nature of service provision, it is important that commissioners encourage provider cooperation and mutual support. For example, if a particular service enters a difficult period in which several staff are injured it is important that they can call on other staff of comparable levels of skill to help get through the difficulties. At present, services tend to work in isolation and even if staff could be borrowed from other local providers, they would be unlikely to have the knowledge and skill required in the more specialised service. Small-scale services have to work together if they are to be sustainable.

86. The role of the National Health Service is to support this process of service development. This means that health bodies should

- Keep contributing the financial resources needed to sustain the transfer of specialist learning disability services to Councils.
- Not undermine the strategy set out in this report by commissioning poor-quality services, especially out of area, themselves.
- Continue to provide sufficient levels of the professional support required to sustain good practice in community based services.
- Provide specialist psychiatric assessment and treatment on a short-term basis, but only as part of an integrated pathway of care for the individual that gets them back into the community.
- Enable fair access to generic health (including mental health) services for people with learning disabilities whose behaviour presents a challenge to services.

Staff training

87. A key contribution to local capability is that staff working with people whose behaviour presents a challenge have adequate training. Many services at present attempt to deal with the challenge they face by adding more and more staff at greater and greater cost. Instead, commissioners should fund higher levels of skill through training. All services will need staff who have enough understanding of the causes of challenging behaviour to prevent it arising or getting worse. This means that they are trained in person-centred approaches, including

- *Person-centred active support*[74]
- *Positive behaviour support*[75]
- *Total communication approaches*[76]
- *Recognising and responding to mental health problems*[77]
- *Person-centred planning*[61]

88. There has been a substantial growth in training in ‘reactive management’ (see paragraph 61) through training in physical intervention[78]. The risk of training staff in physical intervention without training in the preventative approaches listed above is that staff will use them when prevention was possible, with consequent damage to the person’s quality of life. Training in physical intervention should always be based on training in person-centred approaches.

89. A consistent message from service-providing organisations is that the present emphasis in National Minimum Standards on achieving targets for numbers of staff trained at National Vocational Qualification level 2 is not helpful. NVQs are seen as too general, and too heavily influenced by assumptions relevant to services for older people, to be as useful as they should be for staff supporting people with learning disabilities whose behaviour presents a challenge. The Learning Disability Awards Framework is not sufficiently flexible to allow priority to the needs of this group of service users. Using almost all the available funding to train staff at the most basic level makes it harder to meet the needs of people whose behaviour presents a challenge now.

90. New proposals, being developed by the Valuing People Support Team and Skills for Care, for Learning Disability Qualifications to replace the Learning Disability Awards Framework and development of the content of NVQs will provide a more flexible route for front-line staff. Greater emphasis ought to be possible in this new approach on the skills needed to work with people whose behaviour presents a challenge.

91. Good models already exist to pool local resources to provide training at this level for staff from all agencies involved in serving people with learning disabilities. For example, in Cambridgeshire, staff from any organisation working with people whose behaviour presents a challenge can take part in training provided locally to help them improve their practice.

92. There is also a need for training at a more advanced level, particularly for first-line managers and for members of special challenging behaviour support teams. Examples of this are degree and postgraduate level courses provided at, for example, the Universities of Kent, Manchester and London. These are typically multi-disciplinary courses which aim to integrate person-centred approaches with specialist knowledge of challenging behaviour and mental health needs. The Sector Skills Councils should support service development by recognising more specialised and advanced courses in challenging behaviour and specialised training at a more advanced level than NVQ2 should be a requirement where people present challenging behaviour.

Support for local agencies

93. The Commission for Social Care Inspection and the Healthcare Commission have responsibilities for regulating and improving the quality of services received by people with learning disabilities whose behaviour presents a challenge and for the quality of commissioning. These Commissions plan joint work in learning disabilities which will include a focus on the issues raised in this report. The Department of Health also provides support through the Valuing People Support Team (part of the Care Services Improvement Partnership) to assist local authorities and health bodies to improve

services. The Valuing People Support Team plans a programme of work to support implementation of the recommendations of this report.

94. The Department of Health has also provided guidance on commissioning for health and wellbeing[79]. This identifies eight steps towards effective commissioning, viz.

- Putting people at the centre of commissioning
- Understanding the needs of populations and individuals
- Sharing and using information more effectively
- Assuring high quality providers for all services
- Recognising the interdependence between work, health and well-being
- Developing incentives for commissioning for health and well-being
- Ensuring local accountability
- Building capability and leadership.

The proposals made in this report are consistent with these steps and provide a more detailed statement of what is required to achieve effective commissioning of services for people with learning disabilities whose behaviour presents a challenge.

Conclusion

95. In the first version of this report, it was argued that challenging behaviour was an acid test of the policy of community care. Whether community services continue to get better depends in part on how they respond to challenging behaviour, not just in the small number of people who present exceptional problems at any one time, but throughout their service. If they develop the capacity to work with people who present challenges in small, local services they will keep the size of the problem to a minimum and they will provide a good service to individuals in both their mainstream and specialised services. Developing good local services will not be cheaper, overall, than institutional care but it will be more efficient because it will achieve more. If local services are not developed then a trickle of expensive out-of-area placements will become a rush as more people are excluded from mainstream community services by being defined as unmanageable in the community. Large amounts of money will be tied up in buying less good services. The policy of community care will be said to have failed.

96. Although the overall policy of replacing institutional care with better services in the community has worked, people with learning disabilities whose behaviour challenges are among those most at risk of services breaking down. More needs to be done to improve the capacity of learning disability services to support people who present challenges. Service models are available to do this and there are new and exciting opportunities provided by self-directed services and individual budgets. The critical factor now is to change the nature of commissioning to build and sustain the capacity to meet the needs of people in each area.

Appendices

Appendix 1
Illustrative examples of individual situations and service responses*

Michael Langley is 21. He had been behaving in an odd and antisocial fashion since puberty, and was diagnosed at age 17 as having a mental illness in addition to a learning disability. When his behaviour became too severe to be managed at home he was sent to a distant mental handicap hospital despite his and his parents distress. He remains there whilst his parents try desperately to get their large city to provide a local service.

June Pearson, age 25, had often been sent home from school because she harmed herself, including running through windows and attempting to throw herself downstairs. Individual work from a local specialist challenging behaviour team revealed that she had been sexually abused and needed psychological treatment. Because she disliked large groups of people she behaved better in a small alternative day service. Four years later none of the original behaviour occurs and no new challenges have emerged. Treatment still continues whilst she leads her new life.

Samina Hirag presented severe behavioural difficulties at age 11, and was sent to a long stay hospital at 14, where she spent 19 years, often in a locked ward. An attempt at resettlement resulted in behaviour such as urinating in other people's beds, smearing faeces and minor criminal offences. Staff from a specialist assessment and treatment unit were able to diagnose and stabilise a long standing mental illness and reduce the behavioural difficulties. This work is being successfully continued under a Guardianship Order in a community setting.

Victoria Macconi, who cannot speak, unpicks clothing, curtains and carpets when she is in a situation she dislikes. Despite good evidence that the behaviour disappears in a preferred setting, managers are still searching fruitlessly for a way to modify her behaviour in the unsuitable setting, owing to the difficulty of funding an alternative.

Adam Brown, who has a severe learning disability, had to leave home at the age of 12 because his mother could no longer handle his aggressive outbursts after his father left them. 10 years later he is living in a staffed house nearby and has supported work in a canteen. Constructive individual work has enabled a new relationship with his mother to begin. Now they are helped to spend time together at weekends and are planning occasional overnight stays.

Staff in a small house have tried for 3 years, with some success to modify the eye poking behaviour of Winston Attwell. Without support from their manager however, including access to specialist behavioural treatment and meaningful day activity, they are becoming disillusioned and Winston's behaviour is deteriorating.

George Benson is 19 and had attended a special school because of his learning disability. He set two fires in his group home. He was held on remand in prison whilst alternatives to custody were sought. During this period he was bullied and sexually assaulted and now suffers from severe post traumatic stress disorder. The Court is exasperated by the failure of local services to respond, yet do not wish to release him in the absence of support or without the possibility of specific treatment for his fire-setting. After 8 months on remand the health authority agreed to fund his transfer to a specialist assessment service. He was transferred under Section 35 of the Mental Health Act (1983).

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[*] These are not the individuals' real names.

Appendix 2
A Charter for people with learning disabilities who have challenging behaviour or mental health needs

1. Standards and charters applying to other people shall also apply to people with learning disabilities and challenging behaviour or mental health needs.

2. Services will ensure that each person is treated as a full and valued member of their community, with the same rights as everyone else and with respect for their culture, ethnic origin and religion.

3. Services will be individually-tailored, flexible and responsive to changes in individual circumstances and delivered in the most appropriate local situation.

4. Services will strive to enable people to live in ordinary homes, and enjoy access to services and facilities provided for the general community.

5. Services will be provided by appropriately trained, qualified and experienced staff who will help the people they serve to develop fully in all aspects of their lives.

6. Services will be delivered in the least restrictive manner capable of responding to individual needs.

7. Services will strive to continually improve, using the latest research to provide the best treatment, care and support.

Bibliography

1. Department of Health. Services for people with learning disabilities and challenging behaviour or mental health needs: Report of a Project Group (Chairman: Prof J L Mansell). London: Her Majesty's Stationery Office, 1993.
2. Department of Health. Valuing people: a new strategy for learning disability for the 21st century. London: The Stationery Office, 2001.
3. Department of Health. Our health, our care, our say: a new direction for community services. London: The Stationery Office, 2006.
4. Broadhurst S, Mansell J. Organizational and individual factors associated with breakdown of residential placements for people with intellectual disabilities. *Journal of Intellectual Disability Research* 2007;51(4):293-301.
5. Department of Health. Statistical Bulletin: Community Care Statistics 2004 Supported Residents (Adults), England. London: Department of Health, 2004.
6. Mitra I, Alexander R. Out-of-area placements: implications of psychiatric services in learning disability. *Psychiatric Bulletin* 2003;27:382-385.
7. Beadle-Brown J, Mansell J, Whelton B, Hutchinson A. People with learning disabilities in 'out-of-area' residential placements: 2. Reasons for and effects of placement. *Journal of Intellectual Disability Research* 2006;50(II):845-856.
8. Ritchie F, Goodman N, Nix J, Bowyer A. 'Out of area, out of sight?' Review of out of area placement arrangements made by Social Services and Health for people with learning disabilities from the West Midlands. Birmingham: Birmingham and The Black Country Strategic Health Authority and West Midlands South Strategic Health Authority, 2005.
9. Hassiotis A, Jones L, Parkes C, Fitzgerald B, Kuipers J, Romeo R. Services for people with learning disabilities and challenging behaviour from the North Central London Strategic Health Authority area: full report of the findings from the scoping project. London: North Central London Strategic Health Authority 2006.
10. Association of Directors of Social Services. Pressures on learning disability services: The case for review by Government of current funding. London: Association of Directors of Social Services, 2005.
11. Healthcare Commission, Commission for Social Care Inspection. Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust. London: Healthcare Commission, 2006.
12. Healthcare Commission. Data for 2004/2005 NHS Performance Ratings. London: Healthcare Commission, 2006.
13. Robertson J, Emerson E, Pinkney L, Caesar E, Felce D, Meek A, et al. Quality and costs of community-based residential supports for people with mental retardation and challenging behavior. *American Journal on Mental Retardation* 2004;109(4):332-44.
14. Cambridge P, Beadle-Brown J, Milne A, Mansell J, Whelton B. Exploring the incidence, risk factors, nature and monitoring of adult protection alerts. Canterbury: Tizard Centre, 2006.
15. Emerson E, Barrett S, Bell C, Cummings R, McCool C, Toogood A, et al. *Developing services for people with severe learning difficulties and challenging behaviours*. Canterbury: Institute of Social and Applied Psychology, 1987.
16. Department of Health and Home Office. Review of Health and Social Services for Mentally Disordered Offenders and others requiring similar services (Chairman: Dr

John Reed) Volume 7: People with Learning Disabilities (Mental Handicap) or with Autism. London: Her Majesty's Stationery Office, 1994.

17. North West Regional Taskforce on Learning Disability. Breaking the cycle: better help for people with learning disabilities at risk of committing offences: a framework for the North West. Accrington: North West Training and Development Team, 2006.
18. Care Services Improvement Partnership. Positive practice - positive outcomes: a handbook for professionals in the criminal justice system working with offenders who have a learning disability. London: Department of Health, 2007.
19. Care Services Improvement Partnership. Report on Health and Social Care in Criminal Justice Programme Regional and National Performance 2005/6. London: Department of Health, 2006.
20. Whitaker S, Read S. The Prevalence of Psychiatric Disorders among People with Intellectual Disabilities: An Analysis of the Literature. *Journal of Applied Research in Intellectual Disabilities* in press.
21. Ellis D. The epidemiology of visual impairment in people with a mental handicap. In: Ellis D, editor. *Sensory Impairments in Mentally Handicapped People*. Beckenham: Croom Helm, 1986.
22. Kropka BI, Williams C. The epidemiology of hearing impairment in people with a mental handicap. In: Ellis D, editor. *Sensory Impairments in Mentally Handicapped People*. Beckenham: Croom Helm, 1986.
23. Hamilton-Kirkwood L, Ahmed Z, Allen D, Deb S, Fraser B, Lindsay B, et al. Health Evidence Bulletins Wales: Learning Disabilities (Intellectual Disability). Cardiff: National Assembly for Wales, 2001.
24. Wing L, Gould J. Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders* 1979;9(1):11-29.
25. Emerson E, Hatton C. *Moving Out: Relocation from Hospital to Community*. London: Her Majesty's Stationery Office, 1994.
26. Felce D, Lowe K, Perry J, Jones E, Baxter H, Bowley C. The quality of residential and day services for adults with intellectual disabilities in eight local authorities in England: objective data gained in support of a social services inspectorate inspection. *Journal of Applied Research in Intellectual Disabilities* 1999;12(4):273-293.
27. Bradshaw J. Complexity of staff communication and reported level of understanding skills in adults with intellectual disability. *Journal of Intellectual Disability Research* 2001;45(3):233-243.
28. Taylor L, Murphy GH, Oliver C. Self-injurious behaviour: A twenty year follow-up of the first total population study. *Journal of Applied Research in Intellectual Disabilities* 2006;19(3):233-233.
29. Ward F. Modernising the social care workforce - the first national training strategy for England: Supplementary report on learning disability. Leeds: Training Organisation for the Personal Social Services, 1999.
30. Larson SA, Lakin KC. Deinstitutionalization of Persons with Mental-Retardation - Behavioral Outcomes. *Journal of the Association for Persons with Severe Handicaps* 1989;14(4):324-332.
31. Kon Y, Bouras N. Psychiatric follow-up and health services utilisation for people with learning disabilities. *British Journal of Developmental Disabilities* 1997;43(1):20-26.
32. Young L, Sigafoos J, Suttie J, Ashman A, Grevell P. Deinstitutionalisation of persons with intellectual disabilities: A review of Australian studies. *Journal of Intellectual & Developmental Disability* 1998;23(2):155.

33. Felce D, Lowe K. Supporting people with severe learning disabilities and challenging behaviours in ordinary housing. In: Kiernan C, editor. *Research to Practice? Implications of Research on the Challenging Behaviour of People with Learning Disability*. Avon: BILD Publications, 1993:191-207.
34. Royal College of Psychiatrists, British Psychological Society, Royal College of Speech and Language Therapists. Challenging behaviour: a unified approach. Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices. London: Royal College of Psychiatrists, 2007.
35. Ahmed Z, Fraser W, Kerr MP, Kiernan C, Emerson E, Robertson J, et al. Reducing antipsychotic medication in people with a learning disability. *British Journal of Psychiatry* 2000;176:42-46.
36. British Psychological Society. Challenging behaviours: psychological interventions for severely challenging behaviours shown by people with learning disabilities. Leicester: British Psychological Society, 2004.
37. Oliver C, Murphy G, Corbett J. Self-injurious behaviour in people with mental handicap: a total population study. *Journal of Mental Deficiency Research* 1987;31:147-162.
38. McGill P. Challenging behaviour, challenging environments, and challenging needs. *Clinical Psychology Forum* 1993;No 56(June):14-18.
39. Emerson E. *Challenging Behaviour: Analysis and Intervention in People with Severe Intellectual Disabilities*. Cambridge: Cambridge University Press, 2001.
40. Emerson E, Hatton C. Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England. Lancaster: Institute for Health Research, Lancaster University, 2004.
41. Mencap. The Housing Timebomb: The housing crisis facing people with a learning disability and their older parents. London: Royal Society for Mentally Handicapped Children and Adults, 2002.
42. Mencap. Breaking point: a report on caring without a break for children and adults with severe and profound learning disabilities. London: Mencap, 2003.
43. Mencap. Breaking point - families still need a break: a report on the continuing problem of caring without a break for children and adults with severe and profound learning disabilities. London: Mencap, 2006.
44. McGill P, Tennyson A, Cooper V. Parents Whose Children with Learning Disabilities and Challenging Behaviour Attend 52-week Residential Schools: Their Perceptions of Services Received and Expectations of the Future. *British Journal of Social Work* 2006;36(4):597-616.
45. Abbott D, Morris J, Ward L. *The best place to be? Policy, practice and the experiences of residential school placements for disabled children*. York: For the Joseph Rowntree Foundation by York Publishing Services Ltd, 2001.
46. Commission for Social Care Inspection. Growing Up Matters: Better transition planning for young people with complex needs. London: Commission for Social Care Inspection, 2007.
47. Audit Commission. Out of authority placements for special educational needs. London: Audit Commission, 2007.
48. Department of Health. NHS Zero Tolerance Zone: We Don't Have To Take This. Resource pack. London: The Stationery Office, 1999.
49. Williams C, Hewitt P, Bratt A. Responding to the needs of people with learning difficulties whose behaviour we perceive as challenging: the past, present and future - a perspective from Exeter Health Authority. In: Harris J, editor. *Service Responses to*

People with Learning Difficulties and Challenging Behaviour. Kidderminster: British Institute of Mental Handicap, 1991.

50. Johnson D, Cooper B. The Special Projects Team, Sunderland. In: Allen D, Banks R, Staite S, editors. *Meeting the Challenge: Some UK Perspectives on Community Services for People with Learning Difficulties and Challenging Behaviour*. London: Kings Fund Centre, 1991.
51. Reed S, Russell A, Xenitidis K, Murphy DGM. People with learning disabilities in a low secure in-patient unit: comparison of offenders and non-offenders. *British Journal of Psychiatry* 2004;185(6):499-504.
52. Dockrell JE, Gaskell GD, Normand C, Rehman H. An economic analysis of the resettlement of people with mild learning disabilities and challenging behaviour. *Social Science and Medicine* 1995;40(7):895-901.
53. Gaskell G, Dockrell J, Rehman H. Community care for people with challenging behaviors and mild learning disability: An evaluation of an assessment and treatment unit. *British Journal of Clinical Psychology* 1995;34(3):383-395.
54. Xenitidis K, Gratsa A, Bouras N, Hammond R, Ditchfield H, Holt G, et al. Psychiatric inpatient care for adults with intellectual disabilities: generic or specialist units? *Journal of Intellectual Disability Research* 2004;48(1):11-18.
55. Xenitidis KI, Henry J, Russell AJ, Ward A, Murphy DGM. An inpatient treatment model for adults with mild intellectual disability and challenging behaviour. *Journal of Intellectual Disability Research* 1999;43:128-134.
56. Murphy GH, Clare ICH. MIETS: A service option for people with mild mental handicaps and challenging behaviour or psychiatric problems: 2 Assessment treatment and outcome for service users and service effectiveness. *Mental Handicap Research* 1991;4(2):180-206.
57. Clare ICH, Murphy GH. MIETS (Mental Impairment Evaluation and Treatment Service): A Service Option for People With Mild Mental Handicaps and Challenging Behaviour and/or Psychiatric Problems. III: Follow-up of the first six clients to be discharged: Diverse measures of the effectiveness of the service. *Mental Handicap Research* 1993;6(1):70-91.
58. Murphy G, Holland A, Fowler P, Reep J. MIETS: A service option for people with mild mental handicaps and challenging behaviour or psychiatric problems. 1. Philosophy, service, and service users. *Mental Handicap Research* 1991;4(1):41-66.
59. Mansell J, McGill P, Emerson E. Development and evaluation of innovative residential services for people with severe intellectual disability and serious challenging behaviour. In: Glidden LM, editor. *International Review of Research in Mental Retardation*. New York: Academic Press, 2001:245-298.
60. McGill P, Emerson E, Mansell J. Individually designed residential provision for people with seriously challenging behaviours. In: Emerson E, McGill P, Mansell J, editors. *Severe Learning Disabilities and Challenging Behaviour: Designing High-Quality Services*. London: Chapman and Hall, 1994.
61. Department of Health. Planning with people: towards person centred approaches; guidance for implementation groups. London: Department of Health, 2001.
62. Commission for Social Care Inspection. Direct Payments. What are the barriers? London: Commission for Social Care Inspection, 2004.
63. Beadle-Brown J. Direct Payments for People with Severe Learning Disabilities: A Service Case Study and Implications for Policy. *Tizard Learning Disability Review* 2002;7(4):8-15.
64. Duffy S, Casey J, Poll C, Routledge M, Sanderson H, Stansfield J. In control: a national programme to change the organisation of social care in England so that people who

need support can take more control of their own lives and fulfil their role as citizens. London: Mencap, 2004.

65. Poll C, Duffy S, Hatton C, Sanderson H, Routledge M. A report on In Control's first phase 2003-2005. London: In Control Publications, 2006.
66. Commission for Social Care Inspection. Relentless optimism: creative commissioning for personalised care. Report of a seminar held by the Commission for Social Care Inspection on 18 May 2006. London: Commission for Social Care Inspection, 2006.
67. Commission for Social Care Inspection. Time to Care? An overview of home care services for older people in England, 2006. London: Commission for Social Care Inspection, 2006.
68. Haney JI. Toward successful community residential placements for individuals with mental retardation. In: Heal LW, Haney JI, Amado ARN, editors. *Integration of developmentally disabled individuals in the community*. Baltimore: Paul H Brookes, 1988:37-58.
69. Donellan AM, LaVigna GW, Negri-Shoultz N, Fassbender LL. *Progress Without Punishment: Effective Approaches for Learners with Behavior Problems*. New York: Teachers College Press, 1988.
70. Beadle-Brown J, Mansell J, Whelton B, Hutchinson A, Skidmore C. Too far to go? People with learning disabilities placed out-of-area. Canterbury: Tizard Centre, 2005.
71. Newman I, Emerson E. Specialised treatment units for people with challenging behaviours. *Mental Handicap* 1991;19(3):113-119.
72. Mackenzie-Davies N, Mansell J. Assessment and treatment units for people with intellectual disabilities and challenging behaviour in England. *Journal of Intellectual Disability Research* 2007;51(10):802-811.
73. Valuing People Support Team. Person-centred Transition Planning. London: Department of Health, 2007.
74. Mansell J, Beadle-Brown J, Ashman B, Ockendon J. Person-centred active support: a multi-media training resource for staff to enable participation, inclusion and choice for people with learning disabilities. Brighton: Pavilion, 2005.
75. Carr EG, Horner RH, Turnbull AP, Marquis JG, McLaughlin DM, McAtee ML, et al. *Positive behaviour support for people with developmental disabilities: A research synthesis*. Washington: American Association on Mental Retardation, 1999.
76. Foundation for People with Learning Disabilities. Choice Discovered: A training resource pack. London: Foundation for People with Learning Disabilities, 2000.
77. Holt G, Hardy S, Bouras N. Mental Health in Learning Disabilities: a training resource. Brighton: Pavilion, 2005.
78. Allen D, editor. *Ethical approaches to physical interventions: responding to challenging behaviour in people with intellectual disabilities*. Kidderminster: British Institute of Learning Disabilities, 2002.
79. Department of Health. Commissioning framework for health and well-being. London: Department of Health, 2007.

SERVICES FOR PEOPLE WITH LEARNING DISABILITIES AND CHALLENGING BEHAVIOUR OR MENTAL HEALTH NEEDS (REVISED EDITION)

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Integrated Care Pathway for Children and Young People with Complex Physical Healthcare Needs

Contents

Introduction

Overview

This pathway guides community services in meeting the needs of families, children and young people, aged up to 18 years, who have complex physical healthcare needs. This is defined as:
Children (and young people) with complex physical healthcare needs are those who require a range of additional support services beyond the type and amount required by children generally and those usually provided to children with impairments and long-term illnesses.

The vision guiding services is:

Children and young people in Northern Ireland who have complex physical healthcare needs will receive co-ordinated, high-quality, child and family-centred services which are based on assessed needs, manage well the risks to life, promote the child and parents' health and well-being, encourage the social inclusion of children and families, and, where possible, enable them and their families to live ordinary lives.

The Pathway has four strands.

Strand U represents the universal community services that will have been involved to some extent in the care of the child either prior to admission to hospital or to whom the child is referred on discharge. However it is the interfaces between these services and the specialist provision described in Strands 1 to 3 that are covered by the ICP. A service framework covering Children's Health and Social Wellbeing is in preparation by the DHSSPS. This will define the detail of this Universal strand. Links with the universal primary care services are contained in Strands 1 to 3 of the Pathway.

Entering the Pathway

It is presumed that the child and family will enter the Integrated Care Pathway from the acute hospital, although this may not always be so. The child's stay in hospital could be of varying lengths of time and may result from a condition that is present from birth or the result of a trauma in later life.

It is possible that the child may be transferred from a Regional Unit to an Area Hospital. The inter-hospital transfer arrangements are not dealt with in this plan. However re-admissions to acute hospitals are covered under Strand 2.

Strand 1: The first strand of the ICP covers the transfer to community services. This is a crucial phase in the life of the chid and family and handled successfully will contribute greatly to the family's confidence and their trust in services.

Strand 2: Describes the community services available to the child and family. These would usually cover the chronological age range from birth to the child's 18th birthday. This strand entails a range of provision although not every child and family will need or want all the possible services.

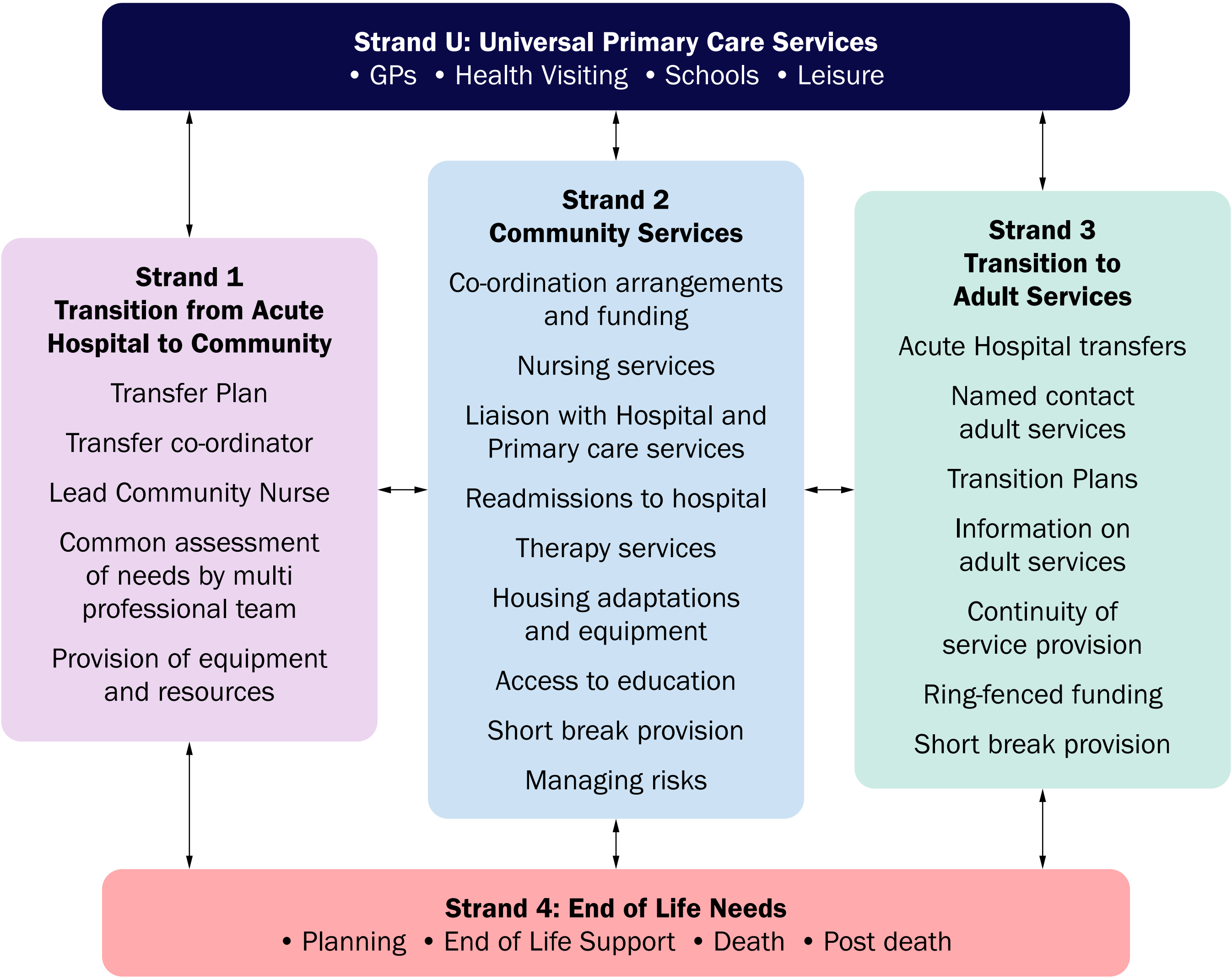
Strand 3: Outlines the transfer arrangements to Adult services. This aspect is the more poorly developed at present; partly because of the relatively few children who have required this strand of the care pathway to date but the numbers will rise in the future as their life expectancy increases. An equivalent Care Pathway for Adult persons would greatly assist the transfer process but this is unavailable at present. HSC Trusts could commence work on such a Pathway based on the model proposed here.

Strand 4: Much of this content of this strand has been taken from the Care Pathway produced by ACT (The Association for Children's Palliative Care: 2004) that covers End of Life and Bereavement. This strand of the pathway could be entered from any of the previous three strands and staff need to be prepared for it.

Introduction

NB The strands are related to one another as the arrows indicate. Actions listed under one strand may have to be commenced under an earlier strand. However for clarity they have been grouped under the strand in which the desired outcomes are listed.

Within the Pathway, a key standard is defined for each Strand and the key outcomes expected. The main actions to be taken by community services are then detailed and a suggested agency or person is assigned responsibility for its implementation. These actions reflect current best practice or actions which are commended in recent reports and research studies. They also embody parental wishes and aspirations. Consideration needs to be given as to how the view of the children and young people are obtained throughout the ICP. The use of Independent Advocacy is a possible option.



Strand U: Universal Primary Care Services

- GPs
- Health Visiting
- Schools
- Leisure

Strand 1
Transition from Acute Hospital to Community

Transfer Plan

Transfer co-ordinator

Lead Community Nurse

Common assessment of needs by multi professional team

Provision of equipment and resources

Strand 2
Community Services

Co-ordination arrangements and funding

Nursing services

Liaison with Hospital and Primary care services

Readmissions to hospital

Therapy services

Housing adaptations and equipment

Access to education

Short break provision

Managing risks

Strand 3
Transition to Adult Services

Acute Hospital transfers

Named contact adult services

Transition Plans

Information on adult services

Continuity of service provision

Ring-fenced funding

Short break provision

Strand 4: End of Life Needs

- Planning
- End of Life Support
- Death
- Post death

Introduction

Recording Actions

The tables of actions within each strand are used to record the services provided to the child and family under each action. Also any deviations from the proposed action should also be noted, such as omissions or improvements that occurred. The reasons for the deviation should be noted.

These records are a crucial tool in sharing information with families and across professionals as well as providing a means of further developing the ICP. In time, it would be possible to specify more explicit criteria regarding service responses, e.g. time limits within a response is made. The Pathway records could then be used for auditing purposes.

In the future, it is hoped to provide the Pathway electronically either for down-loading from an Internet site or as a CD-Rom. This would also assist with updating the content of the ICP or adapting it for localities.

THIS IS THE PATHWAY FOR:

Name of child/family:						
Date of birth:						
Date Pathway started:						
Date of latest update:						

NB. The Regional Assessment Tool to identify Children & Young People with Complex Physical Healthcare should be completed for each child on the Pathway.

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Strand 1: Transition from Acute Hospital to Community Services

Name of Hospital	
Date hospitalised	

Strand 1: Transition from Acute Hospital to Community Services

The key standard for Strand 1 is:

Every child, having been assessed as having complex physical healthcare needs in the hospital setting, should have an agreed transition/discharge plan involving the hospital, community services (both universal and specialist) and the family. The resources required at home should be provided before the child leaves the hospital or as soon as possible thereafter.

Key outcomes – Strand 1

The key outcomes to be accomplished under this strand are:

- Discharge planning should be an integral part of care within the acute hospital setting and commenced from birth or on admission.
- Community services should be notified as soon as practical about the child's admission/transfer/discharge; most likely via the manager of the community children's nursing team.
- A lead community children's nurse should be agreed prior to transition/discharge. It is likely that s/he will act as community care co-ordinator for the family but if not another member of Trust staff should be assigned to take on this role.
- There should be community in-reach to the family in hospital, preferably by a personal visit(s) or via the telephone.

- Planning for the transition/discharge should begin as soon as possible with a multi-disciplinary team meeting and a clear plan devised in agreement with the child, family, hospital and community services.

- Appropriate hospital and community professionals (including the child's GP and health visitor) should be invited to become involved and clear plans should be in place for shared medical care of the child with a community paediatrician and GPs.

- Essential equipment and one month's supplies should be provided to the family/carers before the transfer takes place.

- Competency based training – with underpinning knowledge - should be initiated and overseen by hospital staff and completed for essential carers (including family members) prior to discharge.

- Clear lines of communication should be agreed between the family and community services; family and hospital; hospital and community services.

- A 24 hour contact number(s) should be provided for the family. Ideally this should be of community staff (if available) but otherwise of ward staff in acute hospital.

- A home visit from community nursing staff ideally should take place on the day of discharge or if not possible, a phone call is made followed by a visit the next day.

- The community care co-ordinator will work in partnership with other services to provide a suitable service plan.

Strand 1: Transition from Acute Hospital to Community Services

Record of Actions in Strand 1

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Step-down/transitional protocols from acute care to community services need to be identified in each HSC Trust area. These should also cover discharges from the Royal Belfast Hospital for Sick Children to local acute hospitals as well as to community services.		
Acute	Transition/discharge co-ordinators should be appointed (usually) from nursing staff within each acute hospital. They will liaise across medical consultants and other specialisms, such as allied health professionals and social work.		
HSC Trust	Children who cannot be discharged from hospital due to the lack of community provision should be notified to the relevant commissioning board. HSC Trusts should ensure that they are fulfilling their responsibilities under the Children Order to assess and review children in these circumstances and plan to meet their needs.		
Acute/ Community	Parents need to be informed on the procedures to be followed with respect to obtaining funding from commissioners and the recruitment and selection of any healthcare assistants who may be required.		

Record of Actions in Strand 1 cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Acute/ Community	Parents need to be given a clear and realistic indication of the supports that will be available to them on discharge from hospital and the demands likely to be placed on them.		
Acute/ Community	A lead community nurse should be identified for each child referred from hospital who will most likely act as community care co-ordinator[1]. The lead nurse will liaise with the discharge co-ordinator in the hospital and provide community 'in-reach' to the family.		
Community	A local, named community paediatrician should be identified who will co-ordinate medical care, e.g. with GP.		
Community	A joint assessment of support needs at home and community settings will be undertaken by the hospital staff and the lead community nurse in conjunction with the parents. The lead nurse will involve other community colleagues in this as appropriate – social workers and AHPs – and the voluntary sector. Consideration needs to be given to Understanding the Needs of Children in Northern Ireland (UNOCINI) as the core assessment for children and young people. The specialist Nursing assessment will link with UNOCINI as required, enhancing the information already available.		

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[1] See Key Worker standards produced by CCNUK. **http://www.ccnuk.org.uk/skins/CCNUK/downloads/keyworker.pdf**

Strand 1: Transition from Acute Hospital to Community Services

Record of Actions in Strand 1 cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Community	The lead nurse in conjunction with community colleagues will order the provision of equipment and supplies and ensure their delivery prior to the child's transfer home, subject to the parent's preferences.		
Community	Assessments are undertaken on any housing adaptations that may be required. Arrangements are put in place to facilitate the child's care on an interim basis.		
Community	Pharmacy arrangements are identified including out-of-hours arrangements and procedures for reviewing medication.		
Community	The recruitment and training of healthcare assistants will be undertaken as required. Support staff rotas will be drawn up and provided in advance to the family.		
Community	A 24 hour emergency contact numbers should be provided for the family. This could be within the acute hospital for weekends and night-time. Hospital staff need to be provided with contact numbers of community staff.		

Record of Actions in Strand 1 cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Acute/ Community	Nursing teams will train parents in any necessary procedures, using agreed evidence based protocols. These protocols will be available in writing and shared between nursing teams who may be involved with the child.		
Acute	The hospital discharge or transition co-ordinator will maintain contact with the family for a minimum of one month via personal visits or telephone calls. This contact could be maintained for longer if felt appropriate by the co-ordinator and the family.		
Community	The support plan agreed prior to the transfer should be reviewed within two weeks of the child's transfer and thereafter at agreed intervals (see Strand 2). The discharge co-ordinator should be invited to the first review.		
Community	The health visitor and school nurses should be informed of the discharge plans.		
Community	Plans for short breaks are developed in conjunction with parents (see Strand 2 section h).		

Strand 1: Transition from Acute Hospital to Community Services

Comments/Notes on Strand 1

Date	Person making note	Comment/Note

Strand 2: Community Support Services

Date first discharge from acute hospital (if appropriate):

Strand 2: Community Support Services

The key standard for Strand 2 is:

Every child and family should have a multi-agency support plan agreed with them for the delivery of co-ordinated actions to meet their individual needs. This plan should be regularly reviewed. They should be facilitated to enjoy a good quality of life as a family.

Key outcomes – Strand 2

The key outcomes to be accomplished under Strand 2 are:

- Families will have access to up-to-date, accurate information, in a range of accessible formats, about the range of services and supports available to them in their locality. All professional staff with whom families come in contact, will also have this information.

- Families will be allocated a named contact person who will co-ordinate the supports available to families. This role should be included in the person's job description and protected time allocated for this function.

- Each family will have a named 'core group' of professionals; those who have most contact with the child, such as teacher, therapist, social worker or nurse.

- The support plan will be drawn up in conjunction with families and reflect their aspirations and needs for their child and for the family.

- A holistic and multi-agency approach will be used by community staff to record the outcomes of assessments, reports and reviews, thereby avoiding the need for multiple procedures and record forms. These records, which will include the Assessment of the child's and family's needs, will be held by parents and should accompany the child into different settings/agencies thus avoiding parents having to repeat information. (NB This may require a change to existing professional practice around record keeping.)

- The core group including the named contact will meet with parents as required to review service plans but at a minimum of every six months. Copies of these plans will be made available to families and all relevant service personnel. Parents will be able to request a review at any time. These reviews could be done in conjunction with other required reviews, such as Looked After Children reviews.

- Strategies for managing risks will be developed in conjunction with family carers and shared with all relevant personnel and agencies. These should balance safety with opportunities of ordinary living and be regularly reviewed.

- The children will have timely access to hospital and GP appointments.

- The necessary adaptations, equipment and supplies are available to families on a timely and reliable basis.

- The child has access to educational and leisure activities.

- Carers will be informed of their right to have an assessment undertaken of their needs as a carer.

- Carers will be informed about Direct Payments and assisted in making a decision about the appropriateness to them.

- Opportunities are provided for parents to have a break from caring.

- The emotional well-being of parents and siblings, and their quality of life is a major focus of reviews and the provision of advice and support.

Strand 2: Community Support Services

Record of Actions in Strand 2 (NB In this Strand, the actions are grouped into nine sub-strands).

A) KEY ACTIONS – Co-ordination of services

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Each family should be allocated a staff member who will act as the main point of contact for the family and the co-ordinator of service inputs. The goal is to provide a co-ordinated approach to support and care. The co-ordinator will be the professional who has most ongoing contact with families and will introduce them to other relevant services and act as a conduit of information for other services. Community children's nurses may continue to fulfil this role (this may need to be made more explicit than at present).The person could also be from voluntary/statutory provision if more suited to role.		
HSC Trust	There may be scope to combine the role of co-ordinator with some of the functions of care manager as in Adult Services. For example, there would be advantages in co-ordinators having access to budgets that can be used to provide emergency short break or augmented home supports on a short-term basis. This funding could be channelled through nursing budgets as bank/relief staffing.		

A. Key actions – Co-ordination of services cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	An up-to-date, electronic directory of services and supports should be prepared for each HSC area with contact details of personnel. Copies or print-outs of this should be given to all families and be made widely available to all professionals with whom families are likely to come into contact.		
Community co-ordinator	Families are given the contact details of local support groups for parents and of young people's advocacy groups.		
Community co-ordinator	A 'service map' should be created for each individual child and family and shared with all services and persons who have an involvement with them. Names and contact details should be provided of all those professionals and agencies included in the map.		
Community co-ordinator	Opportunities should be provided for wider family members such as grandparents to be involved in training and planning for the child, e.g. through family-group, case conference.		
HSC Trust Managers/ HSC Board	Annual audits are undertaken of the ICP records to identify improvements to services and their co-ordination. Summary reports should be sent to the Regional HSC Board for onward referral to DHSSPS.		

Strand 2: Community Support Services

Comments/Notes on Co-ordination of Services:

Date	Person making note	Comment/Note

B. Key actions – Nursing and other personal support services

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Each child/family should be allocated to one nursing team who co-ordinates all inputs from nursing services in the community. (Presently a variety of nurses may be involved with the one child and family.) This nurse will liaise with the family health visitor.		
HSC Trust	A funded out-of-hours, on-call service (e.g. up to 10.00 pm) by community nurses for children with complex physical health needs should be provided throughout Northern Ireland. HSC Trusts should assess whether it is required in their area.		
Community Nursing/Acute	Opportunities should be made available to nurses within acute and community settings (e.g. CNLD, district nurses) to develop additional knowledge and competencies in working with children who have complex physical health needs, and in supporting their families.		
Community Nursing/Acute	All nurses should be inducted and mentored in the provision of nursing services to the children to whom they have been allocated, including relief and bank staff. A robust training plan needs to be in place involving acute hospital staff if appropriate. Evidence-based practice should be followed, e.g. contained in relevant care pathways for the particular condition if available[2].		

[2] The Contact a Family organisation has a useful directory of rare conditions that can assist practitioners in accessing information in a family-friendly format.
http://www.cafamily.org.uk/about.html

Strand 2: Community Support Services

Comments/Notes on Nursing and other personal support services

Date	Person making note	Comment/Note

C. Key actions – Access to Hospital and Community Clinics

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Hospital clinics should synchronise their appointment systems as far as possible, so that families make a minimum number of visits to hospitals/clinics. For example, when multiple appointments are required, these are offered for the same day. Personal Identifiers should make this easier to achieve.		
HSC Trust	Transport pick-ups in rural areas to take children to hospitals should be appropriately timed.		
HSC Trust	Systems are in place to ensure that children and young people who find it hard to wait, do not have to stay unduly at outpatient clinics, general practice surgeries or child development centres. Where appropriate, double booking times or first/last appointment times are available for disabled children.		
HSC Trust	Privacy is ensured when staff are obtaining confidential information about the child and family or when they convey news that may be distressing to families.		

Strand 2: Community Support Services

C. Key actions – Access to Hospital and Community Clinics

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust Schools	Facilities for giving personal care in privacy are available in all locations in health, social care and education services that are used by families with a child who has personal/health care needs.		
HSC Trust	Access to hospital services is regularly audited and improved, in partnership with disabled children and their parents.		

Comments/Note on Access to Hospital and Community Clinics:

Date	Person making note	Comment/Note

Strand 2: Community Support Services

D. Key actions – Readmissions to Hospital

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Children and young people with complex physical health care needs who are prone to health crises should have open access to paediatric wards where they are known for assessment/admission (if beds are available), or they are seen urgently on request in A&E departments and GP practices; e.g. a 'Fast Track' card should be given to these families (e.g. Craigavon Area Hospital use these cards).		
HSC Trust	A standardized record of all the child's care needs is prepared that can be given to the hospital staff on admission.		
Ambulance Service	Ambulance control should maintain a record of the child and the hospital to which he/she should be taken in an emergency.		
Community staff	Contact is maintained between community staff and the child/family, e.g. through healthcare assistants working with the child in the hospital and giving parents a break.		

Comments/Notes on Readmissions to Hospital:

Date	Person making note	Comment/Note

Strand 2: Community Support Services

E. Key actions – Access to therapy services

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Therapeutic interventions are agreed and overseen by appropriately trained paediatric therapists.		
Therapists	Parents or carers, children and young people are active partners in decisions about rehabilitation or therapy services, with agreed goals for what it is intended to achieve and how they can help.		
Therapist	Therapy is delivered in the most appropriate setting, which may include the home if this suits the child or young person; or where children and young people attend educational settings it is offered within that setting, and strategies are developed with teachers who support the child's full learning experience. Otherwise therapy appointments are offered outside of school hours to ensure a minimum absence from school.		
Therapists	Protocols are agreed for the delivery of interventions by teachers and learning assistants.		

E. Key actions – Access to therapy services

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
AHP Managers	Reviews are undertaken of local therapy services in order to: a) Promote self-referral, simplifying the care pathway, and reduce excessive waits that may affect a child's development; b) Improve administrative systems and processes for referral and discharge, and the effectiveness of outcomes of different therapeutic regimes, such as group sessions, and c) Ensure that the supply of timely therapy services is sufficient and resourced to meet the needs of children and young people who require it, based on assessed needs. This will involve increased capacity to ensure that all children and young people attending early education settings and mainstream or special schools have equal access to therapy.		

Strand 2: Community Support Services

Notes on access to specific therapeutic services

Therapy service – additional action steps	Details of Action taken with dates	Reasons for deviation

Comments/Notes on Access to thearpy services:

Date	Person making note	Comment/Note

Strand 2: Community Support Services

F. Key actions – Access to Housing adaptations and Equipment

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Consideration of housing, community equipment and wheelchair needs is included in the overall planning of community services for children and their families. Multi-agency partnerships are in place to facilitate this.		
HSC Trust	Equipment and assistive technology is tailored to the individual needs of the child and their future development. (NB These should not be means-tested.) These should be provided on a timely basis.		
HSC Trust	Parents and other carers are given training and support in the use of the equipment and assistive technology, including who to contact in an emergency and out-of-hours.		
HSC Trust/ Partner agencies	The children are able to use/access the equipment and assistive technology they need in **all** places they typically spend time (e.g. school, home, short-term care settings, and leisure settings).		
HSC Trust	Deliveries of bulky health equipment and supplies are sufficiently frequent so that families are not required to store large amounts in the family home. Local emergency stocks of health equipment/supplies are obtainable 24 hours a day.		

Comments/Notes on Access to Housing adaptations and Equipment:

Date	Person making note	Comment/Note

Strand 2: Community Support Services

G. Key actions – Access to Education

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	The child's co-ordinator (or CCN) is involved in planning educational placements and in the statementing process. Any necessary equipment should be available in school.		
Named contact HSC Trust	The child's class teacher and/or support assistant, along with the school nurse if there is one, should be considered members of the core team of professionals and should be involved in the development and review of a common support plan for the child and family.		
Community Nursing/ Schools	Written protocols around transporting the children to/from school and for dealing with medical emergencies should be developed by community health personnel and school staff. Induction training is provided in their use.		
HSC Trust	HSC Trusts and Education need to work in partnership with regards to training and supervision of Additional Special Classroom support who provide care to the child while in the school setting.		
Named contact HSC Trust	Funding arrangements are in place to provide additional support to the family during school holidays or when the child is at home for periods of time due to illness etc.		

Comments/Notes on Access to Education:

Date	Person making note	Comment/Note

Strand 2: Community Support Services

H. Key actions – Short break Provision

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Social Worker	An assessment is undertaken of the child/young person's need for short breaks and their preferences for the form these take.		
Social Worker	An assessment of Carer's needs is undertaken and regularly reviewed. This should include the need for short breaks. Negotiation may be required to reconcile the wishes of young people and family carers.		
Social Worker	Families are informed about Direct Payments and how they can be used to provide breaks from caring.		
HSC Trust	Families should be informed of all the short break options offered by statutory and voluntary agencies. A choice of short breaks should be offered to families, including domiciliary support in the family home, or the child being looked after outside the family home.		
HSC Trust	Consideration should be given to the formal use of wider family members (who are competent to care for the child) in the provision of short break care for which they would receive payment.		

H. Key actions – Short break Provision

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Staff working in existing or planned short break services should receive training in the care for children with complex physical healthcare needs and ongoing support from nursing and AHPs involved with the child.		
HSC Trust	Young people and parents of children with conditions from which they are likely to die before adulthood should be provided with information on the NI Children's Hospice and the services it provides. The decision to avail of such services should be through choice of the child/young person and parents.		
HSC Trust	The nominated social worker convenes regular LAC reviews of children in receipt of care outside of the family home. These meeting should provide an opportunity to review the short break needs of families.		

Strand 2: Community Support Services

Comments/Notes on Short break Provision :

Date	Person making note	Comment/Note

I. Key actions on managing risk

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Service providers	All services contributing to the child's care will regularly assess the risks to the child and to others in the context of their service. Risk management plans will be developed, agreed with the child (where appropriate) and with their parents and the outcomes included in the care plan. These plans will be shared with all agencies.		
Nursing team	The nursing assessment tool, developed for assessing complex physical healthcare needs, acts as one vehicle for the multi-professional identification of risks associated with the child's health care needs.		
Nursing team	For all risks identified within the nursing assessment tool, child-specific risk management protocols should be established and implemented. These will be shared with family and all personnel in all services involved in the support and care of the child.		
Nursing team	An environmental risk assessment is undertaken and completed as part of the discharge planning process from hospital and regularly reviewed.		

Strand 2: Community Support Services

I. Key actions on managing risk cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Multidisciplinary team	At multidisciplinary discharge planning meetings, risks over and above health related risks should be identified, and risk management strategies implemented that are specific to the child and family.		
Multidisciplinary team	Risk management arrangements should be reviewed at regular intervals as part of any review.		

NB *The Dignity of Risk* handbook published by the Shared Care Network has been devised and developed jointly by the Council for Disabled Children and Shared Care Network. It gives an overview of Health and Safety issues incorporating a rights based approach, includes the latest information on key areas of risk and provides guidelines and examples of good practice. Price: £30.00 (inc. p&p) ISBN 1-904787-22-3 (2004)

See also Jeanne Carlin's (2005) book *'Including me: Managing complex health needs in schools and early years setting'*. London: Council for Disabled Children.

Comments/Notes on managing risk

Date	Person making note	Comment/Note

Strand 3: Managing transitions to Adult Service

Planned Date of Transfer	

Strand 3: Managing transitions to Adult Service

The key standard for Strand 3 is:

Every child and family should have an agreed transfer plan to adult services in both acute hospital and community services, and no loss of needed service should be experienced as a result of the transfer.

Key outcomes – Strand 3

The key outcomes to be accomplished under Strand 3 are:

- Planning for the transfer should commence around the young person's 14th birthday or earlier as required. Families need support and reassurance as they prepare for change and as they work through it.

- A 'transitional care nurse' is appointed in community services to assist with the preparation for change.

- Adult services in acute and community settings should be notified at this time about the pending transfer and appropriate staff invited to attend futures planning meetings.

- In the acute sector, a hand-over meeting should take place between the two medical specialists – children and adult - the young person and the family. Ideally one lead consultant will be named if there are two or more consultants involved with the child. Likewise a transitional care nurse from the children's ward will be identified to liaise with adult wards.

- The young person and family will be given the opportunity to familiarise themselves with the adult ward and nursing staff.

- Ideally one named contact will be identified from adult services in the community.

- The named contact for the young person and family from children's services will convene a futures planning group for the young person which will include representatives from adult services – such as therapy, social work, day centre as anticipated. Prior to the transfer, they will meet at least annually to review the transition plan.

- The group from HSC will liaise with their counterparts in education to co-ordinate transition planning. One common Transition Plan will be prepared.

- Clear lines of communication should be agreed between the family and adult community services; family and hospital; hospital and adult community services.

- HSC Trusts will anticipate the budgets that are required to provide continuity of service provision for assessed needs when the young person transfers from Children to Adult Services. The families will not be wait-listed for services that they continue to need.

Strand 3: Managing transitions to Adult Service

Record of Actions in Strand 3

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Acute Hospitals	Within acute hospitals, a common age of transfer is introduced across medical specialisms for the transfer of children with complex physical healthcare needs to adult services, preferably around 18 years of age.		
Acute Hospitals	Within acute hospitals, procedures should be put in place to plan for the transfer of children with complex physical health needs to adult medical and nursing services. This could include: • A named transition nurse from the Children's ward. • A hand-over meeting taking place between the consultant doctors, the young person and the family. • A visit to the adult ward to which the young person would be admitted.		
HSC Trusts	In community services, a transitional care nurse is appointed to co-ordinate the transfers from children to adult services. S/he will act as the main point for other team members in each service.		

Record of Actions in Strand 3 cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Named contact	The family's named contact in children's services will be responsible for convening the transition planning meetings with the young person and family, and for maintaining contact with transition planning within education.		
Adult services HSC Trusts HSC Trusts HSC Trusts	An accessible information leaflet should be made available to young people and families that details the adult service options and contact persons. If possible there should be continuity of service provision into the adult years, such as healthcare assistants within home, family placement providers, direct payments. This will require adult services to budget in advance for these needs. Likewise the costs of nursing, therapy, short breaks and other provision needs to be budgeted in advance within adult service budgets.		
Adult services	Appropriate short breaks should be planned by adult services well in advance of the person requiring them.		

Strand 3: Managing transitions to Adult Service

Comments/Notes on Strand 3

Date	Person making note	Comment/Note

Strand 4: End of Life Needs

Strand 4: End of Life Needs

The key standard for Strand 4 is:

Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this as closely as possible.

Key outcomes – Strand 4

The key outcomes to be accomplished under Strand 4 are:

- Children and families should be supported in their choices and goals for quality of life to the end.
- Professionals should be open and honest with families when the approach to the end of life is recognised.
- Joint planning with families and relevant professionals should take place as soon as possible.
- A written plan of care should be agreed including decisions about methods of resuscitation. The Emergency services should be informed. Care plans should be reviewed and altered to take account of changes.

- There should be 24-hour access to pain and symptom control including access to medication. Those managing the control of symptoms should be suitably qualified and experienced.
- Short break options with medical and nursing input will be available to family carers.
- Emotional and spiritual support should be available to the child and the carers.
- Parents should feel in control of events after death and should be enabled to make their own choices, e.g. care of the body and funeral arrangements.
- The needs of siblings and grandparents should be considered and included at the time of death and afterwards.
- Bereavement support should be offered for as long as the family needs.

NB: *The content for this Strand is largely taken from the Care Pathway produced by ACT (2004). Further suggestions are welcome.*

Strand 4: End of Life Needs

Record of Actions in Strand 4

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Core Team	A plan for end of life care should be documented with the family and young person. This will include their needs and wishes. This may have to be done urgently if the child condition deteriorates rapidly but at other times it can be done in advance once a terminal phase is recognised or in response to a family's expressed concerns.		
HSC Staff	A *small* core team of key professionals will be identified to support the family and child. These persons will be selected from those with an involvement with the child and family (in statutory and voluntary services). The team needs to be open and honest with the family about the probability that the child's life is nearing an end.		
HSC Trusts	Someone on the team or known to the team (e.g. palliative care nurse) has the specialised skills and knowledge to support the family in approaching the discussion of death and opening the possibility to the child or young person in order that they contribute actively to the plans.		

Record of Actions in Strand 4 cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trusts	The plan will cover a Personal Resuscitation Plan that outlines the emergency treatment to be used, e.g. by ambulance crews and local A&E Departments. Options around organ donation should be explored and explanations given about post mortems. Parental and child decisions around these issues should be respected.		
HSC Trusts	Written information should be provided to the family about the procedures and entitlements following death; to include registering the death; procedures required for cremation, use of funeral directors who are members of accredited bodies, advice on benefits and entitlements.		
HSC Trusts	The family and the young person will be enabled to choose the environments in which end-of-life care is provided. In Hospice or Hospital settings, family members should have 24 hour access.		
HSC Trusts	The family and team will have 24 hour access to paediatric palliative care specialists and other qualified nursing staff and paediatricians so that symptoms and pain can be controlled* and unnecessary admissions to hospital avoided.		

* Royal College of Nursing. *The Recognition and Assessment of Acute Pain in Children: Implementation Guide*. London: RCN, 2001

Strand 4: End of Life Needs

Record of Actions in Strand 4 cont'd

Responsibility and name of lead person	Action Step	Details of Action taken with dates	Reasons for deviation
Core Team	Decisions around the removal of life prolonging treatments must be taken in full consultation with the child (if appropriate) and the family and the time provided for them to come to a decision.		
Core Team	Around the time of death, the child and family will be given the necessary privacy and space. Professionals should be sensitive to their needs and take their cue from them. The family's cultural and religious beliefs should be respected. The questions and concerns of siblings should be addressed.		
Named Contact	All those professionally involved with the child should be informed about the death. The named contact may do this on the family's behalf if they wish it. This includes the GP, social worker, school, AHPs, short break service and hospital staff. It is important that any department or service expecting future contact with the child are informed so that further letters are not sent out.		

Record of Actions in Strand 4 cont'd

Responsibility and name of lead person	**Action Step**	**Details of Action taken with dates**	**Reasons for deviation**
Core Team	Members of the core team should maintain contact with the family to offer co-ordinated bereavement support through the agency best suited to their needs. Particular care of siblings is needed. Assistance with dealing with secondary losses could be provided, such as loss of friendships, financial hardships, physical ill-health.		
HSC Trusts	Professionals who have been closely involved with the care of the dying child and family will have access to emotional and psychological support.		

Strand 4: End of Life Needs

Comments/Notes on Strand 4

Date	Person making note	Comment/Note

Useful References

Royal College of Nursing. (2001) *The Recognition and Assessment of Acute Pain in Children: Implementation Guide*. London: RCN.

Royal College of Paediatrics and Child Health. (1997) Withholding or withdrawing life saving treatment in children: a framework for practice. London: RCPCH.

Talbot, K. (2002) *What forever means after the death of a child*. London: Brunner-Routledge.

NB The Children's Palliative Care Reflective Model of Supervision can be a useful tool for supporting all those professionals involved with the care of the dying child.

Notes

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CCQI
COLLEGE CENTRE FOR QUALITY IMPROVEMENT

Accreditation for Inpatient Mental Health Services – Learning Disabilities (AIMS-LD)

Standards for Adult Inpatient Learning Disability Units

Standards have been classified as follows:

Type 1: failure to meet these standards would result in a significant threat to patient safety, rights or dignity and/or would breach the law;

Type 2: standards that an accredited unit would be expected to meet;

Type 3: standards that an excellent unit should meet or standards that are not the direct responsibility of the unit.

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Royal College of Nursing
College of Occupational Therapists
mencap The voice of learning disability
The British Psychological Society

A manual of standards written for:
Inpatient services for adults with learning disabilities (excluding long stay/rehabilitation/campus units)

Also of interest to:
People with learning disabilities
Carers
Commissioners
Policy makers
Researchers

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A full copy of this document is available on our website at:
www.rcpsych.ac.uk/aims-ld

Contents

STANDARDS

Section 1:
Patient Journey

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Foreword

We are pleased to introduce the first edition of the standards for Accreditation for Inpatient Mental Health Services – Learning Disabilities (AIMS-LD).

This development coincides with the recent national drive to improve the standards of care in NHS health campuses following the publication of the Healthcare Commission audit report.

These standards are applicable to any inpatient unit that supports adults with learning disabilities who present with mental health needs, challenging and/or forensic type behaviours. The exception to this are those units considered to be ‘homes for life’. A similar document of standards also already exists for Children with Learning Disability.

These standards have been developed from both a literature review and consultation with stakeholder groups which included the service user and carer representatives, professionals, and various professional bodies.

We hope the standards will provide in-patient units with a clear and comprehensive description of best practice in these services. The standards will be subject to annual review which will include feedback from the units that participate in the accreditation programme.

Please join us in promoting high-quality care environments for people with learning disability in all inpatient care settings.

Sabyasachi Bhaumik
Chair of Learning Disabilities Faculty
Royal College of Psychiatrists

Introduction

The need for a quality improvement programme

The NHS funds a range of residential provision for people with a learning disability (LD). This includes:

- NHS-managed admission and assessment units;
- NHS-managed long-stay/rehabilitation units (although there are plans to close those that remain);
- NHS-managed forensic/secure units;
- Units managed by the independent sector, the care of whose residents is funded by the NHS.

These vary greatly in terms of size (in relation to the number of residents), staffing levels, level of security, length of stay, case mix of resident group and philosophy of care. They range from therapeutic communities to secure units and from short-stay admission units to "homes for life".

Consistent with this diversity, LD services are managed by a range of organisations. Within the NHS, the commonest configuration is for them to be a small part of an NHS Trust that manages mental health services. Organisations that manage independent sector units vary greatly in size. Commissioning of LD residential care is poorly developed and haphazard. One result of this diversity, and of the marginalisation of LD services, is that LD units tend to be isolated from one another both geographically and in organisational terms.

In England, NHS-managed long-stay LD units have attracted the attention of the media and of the Healthcare Commission because of poor standards of care and of institutionalised practices that created a culture where abuse was more likely to occur. Recent, high profile press coverage has dented public confidence in adult learning disability inpatient units in general. The Learning Disability Faculty discussed at length what the College could do both to improve the quality of care, and to demonstrate that care practices in these units are generally sound. As a result, it asked the College Centre for Quality Improvement (CCQI) to develop a new standards-based quality improvement network for inpatient units for people with learning disabilities and mental health needs. The Royal College of Psychiatrists' CCQI currently manages a range of programmes of work in mental health services, each tailored to meet the needs of the specialty. As well as identifying and acknowledging services that demonstrate high standards of organisation and care, these programmes support and enable services to achieve higher standards; as a result, quality in services is driven up.

Key Principles for a quality improvement initiative in LD

These are the same as those that underpin the other quality networks managed by the CCQI, namely:

- ***Local ownership and trust***: the process is owned by front-line staff and incorporates true peer-review.
- ***Engagement***: the system engages all relevant groups, including all staff who work on the unit, senior service managers, people with learning disabilities, and carers.
- ***Credibility***: the standards and associated criteria on which the programme is based are explicit and the process of applying them is transparent.
- ***Responsiveness***: feedback to participating units is prompt and includes advice and support about how to meet standards. Networking is encouraged through newsletters and an e-mail discussion group.
- ***A focus on development***: although the process of review is rigorous, and the feedback honest, the purpose of the process is to support and help units to improve in line with the standards.

An overview of the programme

Membership

Membership is open to any LD unit that is managed by either the NHS or the independent sector. The common criterion is that the care received by the residents of the unit is funded by the NHS.

The standards and associated criteria

This manual of standards has been produced to underwrite the accreditation processes. They have been developed from a literature review and in consultation with stakeholder groups. Care has been taken to include information from a wide range of sources and to take into account the views of staff, people with learning disabilities, and carers. The standards and criteria will be subject to annual review.

The full set of standards is aspirational and it is unlikely that any unit would meet all of them. To support their use in the accreditation process, each criterion has been categorised as follows:

- **Type 1:** failure to meet these criteria would result in a significant threat to safety, rights or dignity and/or would breach the law;

- **Type 2:** criteria that an accredited service would be expected to meet;

- **Type 3:** criteria that an excellent service should meet or criteria that are not the direct responsibility of the service.

The standards and associated criteria are also available on our website: http://www.rcpsych.ac.uk/aims-ld.

The self-review audit tools

A series of audit tools are used to support the measurement of adherence to the standards and associated criteria. These include:

- **A carer questionnaire:** a series of questions about carers' experiences of different aspects of the services provided by the unit e.g. the assessment process, the environment, the provision of information and choice.
- **A staff questionnaire:** a series of questions about unit staff's experiences of different aspects of the service e.g. staff support and training.
- **A referrer questionnaire:** a brief series of questions for referrers about different aspects of the referral.
- **A Unit Manager questionnaire:** a series of questions for unit managers relating to different aspects of the service e.g. staffing, systems, policies and procedures.
- **A patient tracer:** an audit of a sample of case notes against a detailed checklist of standards.
- **A checklist:** a checklist of policies, protocols and procedures that govern service provision.
- **A staff training matrix:** a checklist of training attended by each member of unit staff.
- **An environmental audit.**

Stages of the accreditation process

Stage 1:	**the unit undertakes a self-review** using a range of audit tools (as described above).
Stage 2:	**the unit hosts a peer-review visit** by a multi-professional team that includes a person with learning disabilities or carer.
Stage 3:	**the unit receives a written local report**, which will include a statement about performance against the standards, highlight issues that need attention, and include advice and comments from the review team. Subsequent feedback will also include the decision about accreditation status.
Stage 4:	**the unit begins action planning and implementation of improvements.**

Email Discussion Group and website

Member units have access to advice and support from the Royal College of Psychiatrists and their peers through the programme's email discussion group. Email 'JOIN' to aims-ld-chat@cru.rcpsych.ac.uk to become a member.

Further information can also be found at www.rcpsych.ac.uk/aims-ld.

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Name	**Role / Title**
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Glossary of Terms and Abbreviations

BILD. The British Institute of Learning Disabilities.

Capacity. The ability to understand and give legal consent to an action or arrangement.

Care plans. A care plan will say in writing what help a person needs and who will be providing this.

Carers. Where we have used the term ‘carers’, we mean ‘people who care for or support the person with learning disabilities’. This includes family carers, advocates, befrienders, associates, paid staff (see also **family carer**).

Clinical governance. A systematic approach to maintaining and improving the quality of patient care.

Consent. Agreement to an action or arrangement.

CPA. Care Programme Approach: The process mental health service providers use to coordinate care for mental health patients.

CRB. Criminal Records Bureau.

Family carer. This term is used to refer specifically to non-professional and unpaid carers.

Health Action Plans. A Health Action Plan is a personal plan about what a person with a learning disability can do to be healthier.

Knowledge and Skills Framework. The Knowledge and Skills Framework process involves managers working with individual members of staff to plan their training and development.

MDT. Multi disciplinary team.

Mental Health Act Section 117. Under section 117, health authorities and local social services have a legal duty to provide aftercare for patients who have been on sections 3, 37, 47 or 48, but who have left hospital.

Named nurse. This is a nurse who will have a special responsibility for a patient while they are in hospital.

Person-centred planning. A process of life planning for individuals based on the principles of inclusion and the social model of disability.

Person/People. Where we have used the terms ‘person’ or ‘people’, we mean ‘people with learning disabilities/difficulties’.

POVA. The Protection of Vulnerable Adults scheme.

PRN. ‘Pro re nata’ (as required). This refers to being prescribed medication to take when it's needed, rather than regularly at the same time each day.

<table>
<tr><th>No.</th><th>Standard</th><th>Type</th></tr>
<tr><td colspan="3">**Section 1: Patient Journey**</td></tr>
<tr><td colspan="3">**Pre-admission**</td></tr>
<tr><td colspan="3">**Standard 1: A person who requires inpatient care is referred to the appropriate services, without unnecessary delay.**</td></tr>
<tr><td>1.1</td><td>Written referral criteria clearly specify the function of the inpatient service, and the age groups and problems that the unit does and does not cater for.</td><td>2</td></tr>
<tr><td>1.2</td><td>There is a documented, up-to-date referral procedure for routine referrals, which is agreed with other agencies and services and made available to referrers.</td><td>2</td></tr>
<tr><td>1.3</td><td>Inpatient staff are involved in pre-admission discussions to determine whether or not the unit is suitable for the individual’s needs, taking into account the remit of the unit and the needs of the resident population.</td><td>3</td></tr>
<tr><td>1.4</td><td>Pre-admission assessments are attended by a member of the inpatient unit team.</td><td>3</td></tr>
<tr><td>1.5</td><td>For routine admissions, the unit accesses all of the recent community paperwork that is available on the person.
Guidance: this might include
• mental health and risk assessments;
• details of current medication;
• physical health assessments, and a copy of Health Action Plans;
• existing care plans/person-centred plans/CPAs;
• details of daily living routines and preferences;
• the role of family and carers;
• communication needs and use of communication methods.</td><td>1</td></tr>
<tr><td>1.6</td><td>There is a documented, up-to-date referral procedure for emergency referrals (i.e. people being admitted within 24 hours), which is agreed with other agencies and services and made available to referrers.</td><td>2</td></tr>
<tr><td>1.7</td><td>For emergency admissions, where the person arrives out-of-hours, there is evidence that community assessment paperwork was actively sought the next working day.
Guidance: this might include
• mental health and risk assessments;
• details of current medication;
• physical health assessments, and a copy of Health Action Plans;
• existing care plans/person-centred plans/CPAs;
• details of daily living routines and preferences;
• the role of family and carers;
• communication needs and use of communication methods.</td><td>2</td></tr>
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1.8	Before a routine admission, the person (and their carer) is given the name and contact details of a link person for admission queries.	1
Admission and Initial Assessment		
Standard 2: Throughout the admission process, the person is reassured, welcomed and given the information they require.		
2.1	Before admission, or as soon as they arrive, a member of staff checks that the person has any aids or equipment that they need. *Guidance*: this might include a walking frame or hearing aid.	1
2.2	The person and their carer are met on arrival, shown to an appropriate area and offered refreshments.	2
2.3	The person and their carer are introduced to the member of staff who will be their point of contact for the first few hours of admission.	2
2.4	On the day of their admission, or as soon as they are well enough, the person is given an accessible information/welcome pack that describes life on the unit. *Guidance*: this might include • the purpose of the unit; • methods of treatment; • unit facilities, daily life and programme of activities; choice of food; • personal safety on the unit; • visiting arrangements; • what practical items people need to bring in; • the rights of people who are staying there and what is expected of them, including levels of freedom and restriction; • sleeping arrangements (e.g. shared or single bedrooms).	2
2.5	On the day of their admission, or as soon as they are well enough, the person is shown around the unit at a steady pace.	2
2.6	If the person is detained under the Mental Health Act, on the day of their admission or as soon as they are well enough, they are given written information on their rights, in accordance with section 132 of the Act. *Guidance*: this <u>must</u> include any of the following that were relevant to the person • rights to advocacy; • rights to a second opinion; • right to move hospital; • right of access to interpreting services; • professional roles and responsibilities; • the complaints procedures.	1
2.7	If the person is admitted informally, on the day of their admission or as soon as they are well enough, they are given accessible written information on their rights, rights to advocacy and second opinion, right	1

	of access to interpreting services, professional roles and responsibilities and the complaints procedure.	
2.8	On the day of their admission, or as soon as they are well enough, the person is told the name of their named nurse/care team and how to arrange to meet with them.	2
2.9	If the person is having difficulty settling and would benefit from extra contact with their carer, staff make efforts to facilitate this. *Guidance*: this might include • showing flexibility around visiting times, telephone contact; • allowing carers to stay overnight.	2
Standard 3: A comprehensive initial assessment takes place		
3.1	A physical examination is conducted within 24 hours of the person's admission and this is recorded. *Guidance*: if the examination does not occur (because the person refuses, or because a risk assessment confirms that examination is not possible within this time frame), this is recorded and relevant observations are documented.	1
3.2	A comprehensive physical health review takes place as part of the initial assessment. *Guidance*: if the review does not occur (because the person refuses, or because a risk assessment confirms that examination is not possible within this time frame), this is recorded and relevant observations are documented. The review might include: • details of past medical history (or request made for information from relevant agencies); • a comprehensive review of symptoms; • current medication, including side effects; • lifestyle factors e.g. sleeping, diet, smoking, exercise, sexual activity, alcohol and drugs.	1
3.3	If the person has epilepsy, initial information is gathered and recorded on: • seizure type, frequency and stability; • managing prolonged or serial seizures; • arrangements for use of rescue medication.	1
3.4	The person's initial needs are assessed in relation to mobility e.g. aids and adaptations, exercises etc. and these are recorded.	1
3.5	A documented CPA review/admission meeting is held within one week of the person's admission.	2

Further Assessment and Planning

Standard 4: A process of continual multi-factorial assessment and care planning takes place.

4.1	The person's ongoing assessment takes into account existing information and covers mental and physical (health) well-being. *Guidance*: this must include any of the following that were relevant to the person • past and present mental health problems; • mental capacity; • consent or refusal of consent to treatment; • notable life events (loss, trauma, major changes); • developmental history.	1
4.2	The person's ongoing assessment takes into account existing information and covers social and personal well-being. *Guidance*: this would include any of the following that were relevant to the person • their wishes and expectations regarding their admission; • communication needs; • family/social network/social needs; • the role of carers, supporters and advocates; • individual needs relating to gender, ethnicity, culture or spirituality; • pattern of daily life and activities/ability to carry out activities; • food preferences, including special dietary requirements; • any concerns over living situation/financial worries/employment status.	1
4.3	The person's ongoing assessment takes into account existing information and covers risk and safety issues. *Guidance*: this must include any of the following that were relevant to the person • risk of absconding; • risk of harm to self or others; • risk of vulnerability, exploitation or abuse; • examples of situations under which any challenging behaviour is most likely to occur/historical factors that have contributed to behaviour and any relevant environmental/social/health factors; • forensic history.	1
4.4	The person's assessment takes into account existing information and covers their sensory processing profile and the environments they typically function within. *Guidance*: this might include • sensory based assessment of any challenging or self-injurious behaviours; • sensory based assessment of the events leading to or maintaining the hospital admission; • the use of sensory approaches and environments to help manage challenging and self-injurious behaviours, and promote development of positive regulation and self-management strategies.	2

Standard 5: The person's care and support needs are assessed and planned using person-centred approaches.		
5.1	The person's care plan builds on strengths and is focused on clear and attainable goals, which are recorded.	2
5.2	The person's care plan reflects the needs identified in their assessment.	1
5.3	There are systems for recording unmet needs.	2
5.4	The person's behavioural support plans is individualised and consists of ways of avoiding the need for the behaviour(s) to occur. *Guidance*: these might include prevention and secondary prevention strategies and clear interventions for all to follow.	2
Intervention - Review / Monitoring		
Standard 6: Interventions, outcomes and support are monitored and reviewed in accordance with individual need.		
6.1	Staff monitor and record clinical outcomes and risk at regular intervals, using validated tools. *Guidance:* frequency according to guidance of validated tool.	1
6.2	The person has a minimum of weekly documented sessions with their named worker to review their progress.	2
6.3	The person's care is reviewed and recorded by the multi-disciplinary team at the agreed frequency. *Guidance*: ascertain the frequency that was agreed by the MDT and establish whether this was adhered to.	2
6.4	Review notes record any progress made against the aims of the care plan.	2
6.5	Review notes demonstrate that the care plan is adapted where necessary, in response to the person's individual needs.	2
6.6	The person is given the opportunity to develop a Health Action Plan, (or review their existing one) and this is recorded.	2
6.7	The person is given the opportunity to have access to a health facilitator and this is recorded.	3
6.8	Details of the Health Action Plan are incorporated in the person's care plan.	2
6.9	There is ongoing recorded monitoring in relation to: • help with taking medication;	2

	• health promotion; • dental care arrangements; • advice on sexual health and contraception.	
6.10	The person has their weight and blood pressure recorded at least monthly.	2
6.11	Physical health review examination and investigations including weight and blood pressure are repeated at least annually and this is recorded.	2
6.12	If the person is on antipsychotic medication, they are offered screening for side effects after one month and three months of treatment, and thereafter every six months and this is recorded. *Guidance*: side effects might include movement disorders.	2
6.13	If the person takes certain groups of medication (clozapine, anticonvulsant agents, lithium etc), they are offered regular blood tests in accordance with therapeutic guidelines and this is recorded.	1
6.14	If the person has epilepsy, descriptions of their seizures and frequency are recorded on standardised charts.	2
6.15	Physical investigations are carried out and recorded in accordance with the request of the assessing clinician.	2
6.16	The symptoms, progress and treatment of the person's long-term physical disorder(s) is/are reviewed and documented not less than monthly by medical staff.	1
6.17	Unit staff facilitate the person's access to health services. *Guidance*: this might include assisting with transport arrangements, or accompanying the person if required.	1
6.18	If the person takes medication, their allocated nurse monitors the tolerability and side-effects on an appropriately frequent basis. *Guidance*: ascertain the appropriate frequency for monitoring and establish whether this is being adhered to.	2
6.19	If the person takes medication, the medical team monitors and records the therapeutic response of medication on a weekly basis.	2
Standard 7: The person is able to access a person-centred range of activities.		
7.1	The person has a programme of weekend and evening leisure and exercise activities which are relevant to their needs. This is recorded in their care plan and regularly monitored and reviewed.	2
7.2	Group activities are protected and not cancelled or interrupted.	2

7.3	The person is able to access community-based activities, and are enabled to continue with community activities they were involved in. *Guidance*: activities might include eating out, trips to the cinema, playing sport and going on day trips. Note: this would be subject to risk assessment, where appropriate.	2
Discharge		
Standard 8: The person is discharged from the unit when they are ready.		
8.1	The person's discharge plan is initiated and documented on or before admission.	2
8.2	The person's place of discharge is known before admission and this is recorded.	3
8.3	The person's initial discharge plan includes expected length of stay and a provisional/anticipated discharge date.	2
8.4	The person (and their carer) is fully involved in decisions about the stage at which they will move on from the service and this is recorded.	2
8.5	The person (and their carer) is given timely notification of transfer or discharge and this is documented in their notes.	2
8.6	Local information systems are capable of producing accurate and reliable data about delayed transfers of care.	2
8.7	Delayed discharges are routinely reviewed and action is taken to address any identified problems.	2
Standard 9: The person experiences continuity of care when moving between services.		
9.1	The person's allocated community-based care co-ordinator visits them on the unit during the two weeks prior to discharge and this is recorded.	2
9.2	Inpatient staff make every effort to ensure a smooth transition. *Guidance*: this might include • helping to arrange for people, carers or staff to visit the new setting, to check its suitability; • finding out about statutory and voluntary services that might be helpful to the person (and their carer) once they leave the unit.	2
9.3	A documented discharge meeting/review (e.g. CPA/Mental Health Act Section 117) is held prior to discharge.	1
9.4	Inpatient staff provide other community services (including out of area services) three weeks notice of discharge planning meetings.	2

9.5	In addition to the needs identified through the care planning processes, discharge/aftercare plans record: • the person's preferences for their future living arrangements including social, educational and employment factors; • the care and rehabilitation to be provided; • the name of the care co-ordinator (if further care is required); • the action to be taken if relapse or crises occur.	2
9.6	The person (and their carer) is offered a copy of the written discharge/aftercare plan, and this is recorded.	2
9.7	Within seven days of discharge, a copy of the care plan is sent to all relevant service providers, including the referring agent.	2
9.8	Prior to discharge, the date of the follow-up review is recorded in the notes and communicated to the person (and their carer) and relevant services.	2

Section 2: Structure

Policies, Protocols and Strategy

Standard 10: A range of appropriate protocols are in place to cover clinical, management and interagency working.

<u>Clinical</u> protocols/procedures/strategies are in place for the following:

10.1	The use of person-centred planning tools and systems.	2
10.2	Reviewing whether the person and their named worker are getting on.	2
10.3	Informal patients discharging themselves against medical advice.	1
10.4	Obtaining consent. *Guidance:* this should include a list of activities for which specific written consent is required.	1
10.5	The use of mobile phones, including camera phones.	2
10.6	The use of observation in the context of the prevention and management of challenging/violent behaviour.	1
10.7	The use of seclusion. *Guidance*: this must comply with the Mental Health Act.	1
10.8	The administration of PRN medication.	1
10.9	The use of physical restraint. *Guidance*: this should include advice on its use where a person has a physical condition which might increase the risk to them of collapse or injury during restraint.	1
10.10	Recording/reporting of any incident requiring rapid tranquillisation, physical intervention or seclusion.	1
10.11	Recording/reporting of physical and non-physical incidents.	1
10.12	Reviewing incidents of challenging/violent behaviour. *Guidance*: this might include • a clear description of the behavioural sequence(s); • a measure of the frequency, intensity and duration of the behaviour; • a conclusion about why the behaviour occurred.	2
10.13	Ensuring that post-incident support is available for anyone involved in	2

	an incident or anyone who witnessed it, including people and their carers.	
Management protocols/procedures/strategies are in place for the following:		
10.14	Bed occupancy. *Guidance*: this should include the process for exceeding this level.	1
10.15	Planning menus (in accordance with the good practice guidelines).	2
10.16	Monitoring staff morale. *Guidance*: this might include a system of regularly reviewing sickness levels and/or reasons for staff leaving the service.	2
10.17	Communication between the nursing staff, doctors and other relevant members of the MDT. *Guidance*: this might include handover protocols.	2
10.18	The reporting, investigation and resulting actions of complaints, adverse incidents, and near-misses.	1
10.19	Confidential reporting or ‘whistleblowing’ on abuse or inappropriate care.	1
10.20	Promoting positive sexuality and relationships.	1
10.21	The use of bank and agency staff.	1
10.22	The use of volunteers.	1
10.23	Staff appraisal and supervision.	2
Interagency protocols are in place for the following:		
10.24	The sharing of information between identified personnel and agencies in accordance the Data Protection Act.	1
10.25	Safeguarding adults.	1
10.26	Emergencies requiring Emergency Services intervention.	1
10.27	Access to support after people have been discharged.	3
10.28	Transfer or shared care between LD and generic mental health services.	2
10.29	Transfer or shared care between LD and social care services.	2

10.30	Liaison with general practitioners to investigate non-urgent physical health issues.	2
10.31	Access to primary and secondary health services.	2
10.32	Access to emergency medical care.	1
Standard 11: The service is developing and implementing key strategic initiatives.		
11.1	The service has a strategy for improving its service in line with relevant key national policy and guidance. *Guidance*: sources include the following • *Valuing People: a New Strategy for Learning Disability for the 21st Century* (England only) Department of Health (2001) • *Valuing People Now: be a 3 year strategy and delivery plan building on Valuing People* (England only) Department of Health (2009) • *Putting people first: a shared vision and commitment to the transformation of adult social care* Department of Health (2007) • *Independent Living Strategy* Office for Disability Issues • *Healthcare for All* An Independent Inquiry into access to healthcare for people with learning disabilities , Healthcare Commission (2008) • *A Life like Any Other? Human Rights of Adults with Learning Disabilities* Joint Committee on Human Rights (2008)	2
11.2	The service has a strategy for reviewing and monitoring the action plans that arose from the Healthcare Commission audit. *Guidance*: England only	2
Environment and Equipment		
Standard 12: The service provides an accessible, safe, and comfortable environment.		
12.1	The external sign-posting to the unit is clear.	2
12.2	The internal sign-posting is clear and appropriate to the needs of the people who reside there.	2
12.3	A smoke free environment is provided.	2
12.4	The unit has access to aids and equipment to allow the person to do as much for themselves as they wish, subject to risk assessment.	2
12.5	Relevant assistive technology equipment, such as hoists and handrails, are provided to meet individual needs and to maximise independence in self-care needs.	2
12.6	Confidential case material is kept in locked cabinets, locked offices or securely password-protected on IT systems.	1
12.7	There is a risk assessment that takes place at least annually to ensure	1

	the safety of the clinical environment, including potential ligature points.	
12.8	There is a management plan based around the annual risk assessment to address any shortfalls in the safety of the clinical environment.	1
12.9	The internal design of the unit is arranged to promote a safe environment. *Guidance*: this might include the following • unimpeded sight lines; • measures taken to address blind spots within the facility e.g. mirrors, staffing levels adjusted; • Entrances and exits enable staff to see who is entering or leaving.	1
12.10	There is secure, lockable access to the person's bedroom, with external staff override.	2
12.11	The unit is accommodated on no more than one floor.	3
12.12	Whilst ensuring appropriate levels of security, the environment is open and does not unnecessarily restrict people. *Guidance:* refer to 'Locked Door' and 'Health, Safety and Security' policies.	2
12.13	In any area where rapid tranquillisation, physical intervention and seclusion are used, a fully-equipped crash bag is available within three minutes. *Guidance*: this equipment must includes: • an automatic external defibrillator; • a bag valve mask; • oxygen; • cannulas; • fluids; • suction; • first-line resuscitation medications.	1
12.14	The crash bag is maintained and checked weekly or after use.	1
12.15	All staff are aware of the contents of the crash bag and what each item is used for within an emergency procedure.	2
12.16	A replenished First Aid kit is available on each unit.	1
12.17	An effective system is in place to ensure that people who are staying there, visitors and staff are able to summon help in an emergency. *Guidance*: ascertain what is being used e.g. alarm systems, call buttons, personal alarms, staff observations, two-way radios, and whether this is consistent with the needs of the resident population.	1
12.18	Alarm systems/call buttons/personal alarms are checked and serviced	1

	regularly.	
12.19	A collective response to alarm calls is agreed before incidents occur and consistently rehearsed and applied.	1
12.20	The unit is clean	2
12.21	The unit is in a good state of repair. *Guidance:* There is a record of damage/maintenance issues and evidence of these being rectified in a timely manner.	2
12.22	The unit is welcoming and comfortable.	2
12.22	The unit is arranged in a way that allows optimum use of available space and rooms.	2
12.24	The unit has adequate light.	2
12.25	The unit is a comfortable temperature.	2
12.26	The unit is well ventilated.	2
12.27	Areas which need to be quiet are located as far away as possible from any sources of unavoidable noise.	2
12.28	There is a quiet room with comfortable seating.	2
12.29	The unit offers a range of semi-private and public spaces outside the private bedroom, which allow people a different level of participation with the life of the unit.	2
12.30	There is direct access to a safe outside space. *Guidance*: people do not have to be escorted through other units and the design and security of the outside area is consistent with the needs of the resident population.	2
12.31	The outside space is pleasant. *Guidance*: this might include there being a garden area with seating available for relaxation, stimulating features such as a herb garden, flowerbeds, greenhouse and scented flowers.	2
12.32	People have access to the following: • exercise facilities; • reading facilities; • music facilities; • multi-faith prayer/worship facilities; • catering facilities; • art and craft facilities.	3

	Guidance: if the facility is not located on the unit, consider whether staffing levels generally mean that they are accessible to people who need to be escorted.	
12.33	Entertainment facilities suit a range of personal and culturally-specific tastes. *Guidance*: this might include • daily newspapers and good quality magazines; • board games; • cards; • TV and VCR/DVD with videos/DVDs; • computers and internet access (with supervised, risk-assessed access if necessary). (Note: Subject to documented risk assessment where appropriate).	2
12.34	People can sleep in privacy and separate from the opposite sex.	1
12.35	People have access to lockable storage. *Guidance*: this may include their own rooms or access to a safe on the unit.	2
12.36	There are private, designated spaces for people to receive visitors.	2
12.37	People can make and receive telephone calls in private. *Guidance*: this would be subject to risk assessment, where appropriate.	2
12.38	In spaces where personal and confidential discussions are held, such as interview rooms and consulting/examination/treatment spaces, conversations cannot be heard outside of the room.	2
12.39	There is at least one room for interviewing and meeting with individual people and carers, which is furnished with comfortable seating.	2
12.40	The unit has access to a specific room for physical examination and minor medical procedures.	2
12.41	In services where seclusion is practiced, there is a designated room fit for the purpose. *Guidance*: the room must comply with the following. • allows clear observation; • is well insulated and ventilated; • is clean and in a good state of repair; • has access to toilet/washing facilities; • is able to withstand attack/damage.	2
12.42	The unit is able to meet the individual sensory needs of the people resident there. *Guidance*: this could be provided by having access to sensory rooms, or	2

	to portable sensory trolleys/equipment.	
12.43	The unit environment complies with current legislation on disabled access.	1
12.44	Staff have access to a separate staff room with tea/coffee making facilities, away from the main area of the unit.	2
12.45	All staff are able to take regular allocated breaks during their shift.	2
12.46	All staff have access to lockable storage.	2
12.47	There is a dining area big enough to allow people who are staying there to eat in comfort and to enjoy social interaction, and staff should be able to move freely to enable observation.	2
12.48	Water and soft drinks are available 24 hours a day.	1
12.49	Hot drinks are available to people who are staying there 24 hours a day.	2
12.50	The unit has adequate access to suitable vehicles that it can use to transport people who are residing there e.g. to activities. *Guidance*: ascertain whether level of access meets need.	2
12.51	Any vehicle that is used by the unit to transport people who are residing there is subject to regular MOT checks and services and a record is kept of this.	1
12.52	There is a record that all vehicle drivers are compliant with statutory requirements. *Guidance*: for minibuses an internal driving test is appropriate. Car drivers should have a full driving licence and be insured for business.	1
12.53	There is an established, reliable and effective means of communication during escorted leave. *Guidance*: e.g. two-way radios or mobile phones. (Note: this would be subject to risk assessment, where appropriate).	1
Staffing: Staffing levels, management, organisation and communication		
Standard 13: There are sufficient numbers of appropriately skilled staff.		
13.1	Staffing levels are reviewed on a daily basis. *Guidance*: factors to be considered would include: • levels of observation; • sickness and absence;	1

	• therapeutic engagement; • escorts; • the need to promote people's independence; • training, supervision, mentoring and their requirements for continuing professional development; • consultation, outreach and liaison functions.	
13.2	The unit has an agreed minimum staffing level across all shifts which is met.	
13.3	Extra cover can be arranged, e.g. additional on-call staff in an emergency.	2
13.4	In the event of vacancies, long term sickness or maternity leave, prompt arrangements are made for staff cover.	2
13.5	The unit comprises a core multi-disciplinary team, which is able to meet the needs specified in peoples' individual care plans, and includes representatives from the following professions: • Psychiatry; • Occupational Therapy; • Speech and Language Therapy; • Psychology; • Physiotherapy; • Pharmacy; • Social Work.	2
13.6	The available administrative support meets the needs of the unit.	2
Standard 14: Operational management supports effective care.		
14.1	Each person has a named member of staff who co-ordinates their care and this is recorded.	2
14.2	The unit manager has evidence that all staff have up-to-date CRB and POVA checks.	1
14.3	The organisation supports team-building activities. *Guidance*: this might include an annual team-building session.	3
14.4	The unit manager has control over the unit budget.	2
14.5	Staff have access to a clear, up-to-date line management structure.	2
Standard 15: There are effective systems of communication between staff.		
15.1	There is a nurse in charge who is the point of contact for all unit operational matters relating to that shift, e.g. admissions, discharge and leave.	2
15.2	Each shift handover contains a discussion of risk factors and individual	1

	needs resulting in an action plan for the shift, with individual and group responsibilities.	
15.3	MDT staff are consulted in the development of policies, procedures and guidelines that relate to their practice.	2
15.4	Policies, protocols and guidelines are written and formatted in ways MDT staff find accessible and easy to use.	2
15.5	Policies, protocols and guidelines are disseminated and stored in ways MDT staff find accessible and easy to use.	2

Staffing: MDT and Therapeutic Provision

Standard 16: Therapeutic interventions are available and are provided by appropriately trained / qualified people.

The service is able to access a range of therapies and activities that includes the following:

16.1	Behavioural therapy.	2
16.2	Cognitive therapy.	2
16.3	Communication and social skills.	2
16.4	Complementary therapies (e.g. aromatherapy, reflexology).	2
16.5	Creative Therapies (e.g. art, music, drama, dance).	2
16.6	Dietetic advice.	2
16.7	Family therapy.	2
16.8	Group therapy.	2
16.9	Medication.	2
16.10	Occupational therapy.	2
16.11	Physiotherapy.	2
16.12	Social skills training.	2
16.13	Speech and language therapy.	2
16.14	Sports and exercise.	2
16.15	Activities and opportunities to meet individual’s sensory needs.	2

16.16	Therapeutic interventions are provided by staff who are appropriately qualified to do so.	2
Staffing: Knowledge and Training		
Standard 17: The service provides support, training and supervision for staff.		
New staff/induction.		
17.1	<u>New staff</u> are allocated a mentor/preceptor who oversees their induction.	1
17.2	Before being asked to carry out any clinical work, <u>new staff</u> receive mandatory training in fire, manual handling and basic life support.	1
17.3	All staff who are <u>new to the unit</u> are given an induction handbook.	2
17.4	<u>New staff</u> are given information on Trust/organisational policies, in accordance with their level of responsibility, as part of the induction process.	2
Staff receive up-to-date training and development consistent with their role in the following:		
17.5	The principles of person-centred working.	2
17.6	Communicating effectively with people. *Guidance*: this might include • understanding the person's preferred means of communicating; • the use of different communication methods and visual aids; • the importance of tone of voice; • non-verbal communication; • the use of appropriate language; • active listening techniques; • recognising when people might be suggestible/acquiescing; • recognising when people are communicating distress, and responding to it; • the link between communication and challenging behaviour; • the appropriate use of interpreters.	1
17.7	Understanding learning disability.	2
17.8	Understanding mental health.	2
17.9	Engaging and working with carers, families and advocates.	2
17.10	Empowerment and encouraging independence.	2
17.11	Working in a respectful and dignified way.	2
17.12	Understanding the barriers often faced by people with learning	2

	disabilities and how to help people overcome them, including access to services, personal rights and relationships.	
17.13	The legal rights of people with learning disabilities, according to: • the Mental Health Act 1983 (amended 2007); • the Mental Capacity Act 2005/Adults with Incapacity Act 2000; • the Disability Discrimination Act 2005; • the Human Rights Act 1998; • the UN Convention on the Rights of Persons with Disabilities.	2
17.14	The limits of information-sharing, according to: • data protection; • freedom of information; • confidentiality.	2
17.15	Assessing capacity and gaining consent from people with learning disabilities.	2
17.16	Medicines management.	2
17.17	Recognising and managing swallowing difficulties.	1
17.18	Understanding the mental health problems sometimes associated with learning disability.	2
17.19	A range of pharmacological interventions.	2
17.20	A basic understanding of medical conditions sometimes associated with learning disability.	2
17.21	Recognising the signs of symptoms associated with: • physical abuse; • sexual abuse; • emotional abuse; • financial abuse; • institutional abuse; • self-neglect; • neglect by others.	2
17.22	Helping people with learning disability recognise potentially or actually abusive behaviour in any of their relationships.	1
17.23	The protection of people with learning disabilities, including POVA arrangements.	1
17.24	Culturally sensitive practice, disability awareness and other diversity and equality issues.	2
17.25	The use of outcome measures.	2
17.26	Providing basic psychological and psychosocial interventions (including, but not limited to, conflict resolution/de-escalation, engagement activity	2

	scheduling, group facilitation).	
17.27	BILD-approved training (or the equivalent) on the prevention and management of challenging/violent behaviour.	1
17.28	All staff involved in administering or prescribing rapid tranquillisation, or monitoring service users to whom parenteral rapid tranquillisation has been administered, receive ongoing competency training to a minimum of Immediate Life Support.	1
Unqualified staff.		
17.29	Unqualified staff are encouraged and enabled to develop additional skills. *Guidance*: for example through the Learning Disability Awards Framework/Learning Disability Qualifications/NVQ level 2 and 3 (RJ).	2
General.		
17.30	Teams working together have undertaken the same accredited prevention and management of challenging/violent behaviour training.	2
17.31	The unit has access to advice on tailor-made hold/technique by accredited instructors.	1
17.32	Qualified staff from nursing, occupational therapy, psychiatry and clinical psychology professions are developing the necessary skills to provide a repertoire of basic psychological interventions in line with NICE guidance.	2
17.33	Qualified staff from nursing, occupational therapy, psychiatry and clinical psychology professions receive ongoing training and supervision to provide a repertoire of complex psychological therapies, as defined by NICE guidance.	2
17.34	At least one of the MDT is developing at least one complex psychological therapy, as defined by NICE guidance.	2
17.35	There is clinical leadership training for registered nurses, psychiatrists and other members of the MDT (Band 6 and above).	2
Supervision and appraisal.		
17.36	Staff receive annual appraisal and annual review of their job plan.	1
17.37	MDT staff receive managerial supervision on an agreed basis from a person with appropriate experience and qualifications, according to the guidelines of their respective professional body.	1
17.38	MDT staff receive clinical supervision on an agreed basis from a person with appropriate experience and qualifications, according to the	2

	guidelines of their respective professional body. *Guidance*: a minimum of every 8 weeks.	
17.39	Supervision is linked to personal development plans.	2
17.40	Staff have access to work-related counselling.	2
17.41	Staff have access to a unit-based reflective practice/staff support group to discuss clinical work.	3
17.42	Staff are able to contact a senior colleague as necessary, 24 hours a day.	2
	Budget	
	Standard 18: The unit budgets for training, activities and outings.	
18.1	Training budgets enable staff to meet requirements for their continuing professional development and the 'Knowledge and Skills Framework'.	2
18.2	The inpatient unit has an identified budget for activities and outings.	2

Section 3: Process

Involvement

Standard 19: The opinions and preferences of the people resident in the unit are taken into account in the running of the service.

19.1	The person's individual preferences are taken into account in the initial selection of their named worker e.g. gender.	3
19.2	The person has a choice of who comes to any meetings where their care is being assessed, planned or reviewed, including whether their carer attends. *Guidance*: except in cases where the person's care is subject to the Care Programme Approach, Offender Management and Ministry of Justice requirements.	2
19.3	The person (and their carer) is encouraged to be an active partner in developing all aspects of the care plan, including agreeing aims and interventions and their views and wishes are recorded by the assessing practitioner.	2
19.4	The person is able to be actively involved in choosing and planning the activities they take part in (for example, planning a day trip).	2
19.5	The person (and their carer) play a key role in monitoring, evaluating and reporting the effects of interventions.	2
19.6	The person (and their carer) is comfortable with the way that review meetings/ward rounds are conducted.	2
19.7	Action from reviews is fed back to the person (and their carer) and this is documented.	2
19.8	The person is supported and encouraged to manage their own affairs (e.g. their personal finances) as far as is possible.	3
19.9	The person can be involved in the day-to-day running of the unit if they wish to. *Guidance*: this might include • planning social events; • menu planning, shopping and food preparation; • laying tables, clearing away and washing up; • laundry and housework; • gardening.	2
19.10	There are formal, documented arrangements that provide the person with as much choice and control over their life as possible, including bedtimes and bathtimes, eating and drinking, and how they spend their time.	2

19.11	The person is able to personalise their bedroom e.g. with prints, photographs etc.	2
19.12	There is access to the day room at night if the person is unable to sleep at night.	2
19.13	Choice is only restricted for significant clinical or safety reasons, which are explained to the person and recorded in their care plan.	2
19.14	The person can ask to see a staff member on their own e.g. without other staff or carer present. Note: this would be subject to risk assessment, where appropriate.	1
19.15	The person (and their carer) is actively encouraged to give feedback on the service throughout their admission, and on leaving the service. *Guidance*: this might include via consultation groups, a 'compliments and suggestions' box, discharge questionnaires, satisfaction surveys, follow-up letters etc.	2
19.16	There is a choice of well prepared food that meets nutritional, personal, cultural and clinical dietary needs, e.g. vegetarian, low sugar, kosher etc.	2
19.17	Staff make efforts to find out individual preferences for types of food and style of preparation, including food allergies.	2
19.18	People with learning disabilities are involved and supported in interviewing potential members of the MDT during the recruitment process.	2
Communication		
Standard 20: Staff communicate respectfully and make sure they are understood		
20.1	Staff make sure that they are understood. *Guidance*: for example, by: • using communication methods that are consistent with the person's usual and preferred means of communication; • avoiding the use of clinical language/jargon and abbreviations; • avoiding having too much new information in one sentence; • checking that the person has understood the information by asking them to explain it back, in their own words.	1
20.2	Staff make sure that they communicate <u>respectfully</u>. *Guidance:* for example, by: • being patient and encouraging; • allowing enough time; • avoiding using language that is patronising, infantilising or negative; • speaking to the person first, and only checking with the carer if	2

	something is not clear.	
20.3	The unit has access to professional interpreters who have received training or guidance about learning disability and mental health and recognise the importance of full and accurate translation.	3
Information		
Standard 21: Clear and accessible information relevant to the person is available.		
21.1	The person (and their carer) is provided with enough information to make informed choices about care and treatment. *Guidance:* this might include information about the evidence base, risks, benefits and side effects of intervention options and of non-intervention.	2
21.2	A copy of the care plan is offered to the person (and their carer) in an accessible format and this is recorded.	2
21.3	The person has access to health promotion advice in an accessible format, including advice on diet and exercise, oral health, smoking cessation, and sexual health.	2
21.4	Information is available about a range of mental health conditions. *Guidance:* this might include medications and their side effects, treatment alternatives and their relative effectiveness.	3
21.5	Information is available about local mental health and learning disability services.	2
21.6	Information provided is culturally relevant and sensitive.	1
21.7	Information is clear, up-to-date and available in sufficient quantity.	2
21.8	Information is available about: • how to make a verbal complaint; • how to make a written complaint.	1
21.9	Information is available about: • how to suggest service improvements and enhancements; • how to make a written compliment; • how to make a donation.	2
21.10	There is a board on display showing the photographs, names and roles of staff.	3
21.11	Complaints procedures are well-publicised and user-friendly and help is given on how to follow them.	1
21.12	The person (and their carer) is informed of the procedures that would	1

<table>
<tr><td></td><td>be followed if a disclosure of abuse were made, and they are reassured that they would be taken seriously.</td><td></td></tr>
<tr><td>21.13</td><td>The person is informed of the level of observation that they are under.

<i>Guidance:</i> this should include how it is instigated, the review process, and how the person’s perspectives are taken into account.</td><td>1</td></tr>
<tr><td>21.14</td><td>Staff ensure that telephone messages are passed on to people.</td><td>2</td></tr>
<tr><td colspan="3">Dignity, Ethics,
Consent and Confidentiality</td></tr>
<tr><td colspan="3">Standard 22: The unit applies good practice in regard to consent, capacity, confidentiality and respect.</td></tr>
<tr><td>22.1</td><td>Staff make efforts to establish the person’s capacity on an ongoing basis, including seeking advice from the person’s carer and this is recorded.</td><td>2</td></tr>
<tr><td colspan="3">Consent – where the person is assessed as having capacity.</td></tr>
<tr><td>22.2</td><td>The person is informed by staff of their right to agree to, or refuse any intervention, and the limits of this, and this is recorded.</td><td>1</td></tr>
<tr><td>22.3</td><td>Consent is obtained and recorded.</td><td>1</td></tr>
<tr><td>22.4</td><td>Careful procedures are used to establish that the person has given informed consent.

<i>Guidance:</i> this might include staff checking the person’s broad understanding of what they are consenting to by asking them to communicate this back to them.</td><td>2</td></tr>
<tr><td colspan="3">Consent – where the person is assessed as <u>not having</u> capacity.</td></tr>
<tr><td>22.5</td><td>There is evidence that interventions are only conducted without the person’s consent if:
• it has been established that the person lacks the current capacity to consent to the treatment;
• all other options have been exhausted;
• the treatment is deemed to be in their best interests.</td><td>2</td></tr>
<tr><td>22.6</td><td>Where necessary, documented ‘best interest’ meetings are held for carers, professionals, advocates and relevant others to discuss the situation and support healthcare professionals to reach a decision about how to proceed.</td><td>1</td></tr>
<tr><td>22.7</td><td>When the person is assessed as lacking capacity and is treated against their will, this is conducted within the appropriate legal framework, and this is recorded.</td><td>1</td></tr>
<tr><td>22.8</td><td>If the person lacks capacity and is treated against their will, staff still</td><td>2</td></tr>
</table>

	provide the person (and their carer) with as much information about the intervention as possible and this is recorded.	
Confidentiality.		
22.9	The person is made aware of their rights to access records held by the service.	2
Respect.		
22.10	During the administration or supply of medicines, the person’s privacy, dignity and confidentiality are respected.	2
22.11	Staff are friendly and approachable.	2
22.12	Staff and people who are staying there treat one another with mutual respect.	2
22.13	The person’s privacy and dignity is ensured when receiving intimate care.	1
22.14	The person is able to wash and use the toilet safely, in privacy and separately from the opposite sex.	1
22.15	Assistance with eating food is given individually and discreetly and with care and sensitivity e.g. staff sit with the person they are assisting.	2
22.16	Where necessary, staff provide sensitive advice on clothing, hygiene and personal presentation.	2
22.17	Gender-sensitive groups can be provided.	2
22.18	When any physical examinations are carried out on a person • there is a staff member of the same sex present; • there are a minimum of two staff members present; • the person is comfortable with the staff members who are examining, or their chosen chaperones.	2
22.19	Staff respect the person’s personal space, e.g. by knocking and waiting before entering their bedroom.	2
22.20	The person is supported to practice/follow their own cultural or religious beliefs. *Guidance:* this might include having access to associated items, such as a copy of the Qu’ran, Bible or similar, support to attend services, respecting festivals.	2

External Relationships

Standard 23: Staff liaise with carers and other agencies.

Carers/Families.		
23.1	Inpatient staff advise the principal family carer on how to have access to an assessment of their own needs.	3
23.2	Staff support the psychological and emotional needs of family carers by signposting them to local carers' support groups or counselling services, as required.	3
23.3	Staff explain how carers can contact the unit for extra information, advice or support as needed, including outside of planned meetings.	2
23.4	With the consent of the person, staff and carers meet to update each other on any significant information about the person's care, before and after any leave of absence.	2
23.5	Prior to any leave of absence, staff offer the person and their carer advice on coping techniques and behaviour management techniques, if required.	2
23.6	During any leave of absence, carers can contact unit staff for support.	2
23.7	Unit staff provide carers with advice on using different methods of communication, if required.	2
23.8	Carers are involved in the recruitment process.	2
23.9	Visits from friends, family and others are encouraged and facilitated.	2
Other agencies		
23.10	The assessment identifies the other agencies involved in the person's care throughout the person's stay and following discharge.	1
23.11	Unit staff communicate effectively with referrers throughout the person's stay and following discharge.	1
23.12	There is access to relevant faith-specific support, preferably through someone with an understanding of mental health issues.	3
23.13	The unit has a formal link with a range of advocacy services that includes the Independent Mental Capacity Advocate (IMCA) service.	2
23.14	The person (and their carer) have access to independent advocacy services and staff explain the benefits of using these services.	2

Bibliography

Bedfordshire and Luton Community NHS Trust, Learning Disability Service Investigation by the Commission for Health Improvement

Boulter, P and Dodwell, M (on behalf of the Assessment and Treatment Network) (2008) Benchmark of Best Practice for Assessment and Treatment Networks (currently available at www.ldhealthnetwork.org)

Buckinghamshire Primary Care Trust (2008) Report to the Overview and Scrutiny Committee for Public Health Services: Specialist Learning Disability Health Services

Bolton NHS Primary Care Trust (2007) Benchmark of Best Practice for Behaviour Management

Department of Health (2007) Putting people first: a shared vision and commitment to the transformation of adult social care

Department of Health (2001) Valuing People

Department of Health (2007) Services for people with learning disabilities and challenging behaviour or mental health needs

Department of Health (2007) Good practice in learning disability nursing

Department of Health Mental Health Policy Implementation Guide, National Minimum Standards for General Adult Services in Psychiatric Intensive Care Units and Low Secure Environments

Enfield Primary Care Trust Learning disabilities services (2001) An Information booklet for referrers, draft document

Healthcare Commission (2007) A life like no other: a national audit of specialist inpatient healthcare services for people with learning difficulties in England

Healthcare Commission 2005) Draft three-year strategic plan for assessing and encouraging improvement in the health and healthcare of adults with learning disabilities 2006-9, Consultation

Healthcare Commission (2008) Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust

Joint Committee on Human Rights (2008) A Life like Any Other? Human Rights of Adults with Learning Disabilities

Leeds Mental Health Teaching NHS Trust Learning Disability Directorate (2006) Strategy for Specialist Learning Disability Services

Mencap (no date) Equal Lives for people with a learning disability

Mencap Death by indifference. Following up the *Treat me right!* report

Mencap *Treat me right!* Better healthcare for people with a learning disability

Mind Learning disabilities and mental health problems factsheet

National Autistic Society The review of mental health and learning disability

National Disability Authority (2003) Review of Access to Mental Health Services for People with Intellectual Disabilities

NHS National Patient Safety Agency Listening to people with learning difficulties and family carers talk about patient safety

Northamptonshire Healthcare NHS Trust Inpatient discharge policy

Office for Disability Issues Independent Living Strategy

Prime Minister's Strategy Unit (2005) Improving the life chance of disabled people

Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust Arrangements for in-patient service users who require care in the local acute hospital

Royal College of Nursing (2007) Mental health nursing of adults with learning disabilities

Royal College of Psychiatrists (2004) Psychiatric services for children and adolescents with learning disabilities

Sheffield Trust Hospitals Care Standards author Rosemary Bollands

Surrey and Borders Partnership NHS Trust Benchmark of Best Practice for physical interventions/restraint

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GAIN
GUIDELINES AND AUDIT
IMPLEMENTATION NETWORK

GUIDELINES ON CARING FOR PEOPLE WITH A LEARNING DISABILITY IN GENERAL HOSPITAL SETTINGS

June 2010

FOREWORD

These guidelines have been published by the Guidelines & Audit Implementation Network (GAIN), which is a team of health and social care professionals established under the auspices of the Department of Health, Social Services & Public Safety in 2008. The aim of GAIN is to promote quality in the Health Service in Northern Ireland, through audit and guidelines, while ensuring the highest possible standard of clinical practice is maintained.

These guidelines address the needs of an important and vulnerable group in society and to further this aim we have included an example of a possible implementation plan which we hope will ease the adoption of these guidelines under most circumstances.

This guideline was produced by a sub-group of health care professionals from varied backgrounds and was chaired by Maurice Devine, Nursing Officer at the Department of Health, Social Services & Public Safety (Northern Ireland).

GAIN wishes to thank all those who contributed in any way to the development of these guidelines.

Tom Trinick

Dr T Trinick
Chairman of GAIN

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CARING FOR PEOPLE WITH A LEARNING DISABILITY IN GENERAL HOSPITAL SETTINGS

Introduction

Going into hospital for any reason is a time of anxiety and stress for any of us. People can find that they are in an unfamiliar environment, with unfamiliar people using unfamiliar language. Alongside this unfamiliarity the person may be suffering significant illness and/or pain and consequently, it is a time when people often feel vulnerable.

On such occasions, children, young people and adults with a learning disability may feel even more vulnerable for a range of reasons, including difficulties they may have in respect of communication, difficulties in expressing feelings of discomfort or pain, difficulties with self-management. In addition, a limited understanding of the needs of people with learning disabilities by the hospital staff caring for them increases their vulnerability. Other factors that add to this vulnerability are that the person may have additional health needs such as epilepsy, mental health issues, sensory impairment, compromised nutrition and be at increased risk of choking, all of which are more common in people with learning disabilities.

Current health and social care policy within Northern Ireland is underpinned by the recognition of people with learning disabilities as equal and valued citizens of the country (DHSSPS 2005). Despite this, a range of key publications discussed within the literature review of this document has highlighted the difficulties many people can encounter in accessing and using general hospital services, at times, with grave consequences for people with learning disabilities.

It is therefore intended that these guidelines for care delivery will enhance safe and effective care throughout the journey within the general hospital setting for people with a learning disability.

LITERATURE REVIEW

The next few pages provide a definition of the term 'learning disabilities' and an overview of the published literature on the difficulties people with learning disabilities may encounter when accessing general hospital services, alongside the published recommendations to improve the quality of services. The guidelines contained within this document have been developed in response to the evidence within the published literature.

What is Learning Disability?

The formal definition of people with a learning disability used within Equal Lives (DHSSPS 2005), is as follows:

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.

As a consequence, the individual is likely to experience difficulty in understanding new or complex information or learning new skills. The individual may also have difficulties with social and/or communication skills, with carrying out activities of daily living independently and may have associated physical and sensory disabilities.

Within N. Ireland, there is a population of approximately 26,500 people with a learning disability of whom about half are aged between 0 – 10 yrs (DHSSPS 2009). For a range of reasons people with learning disabilities are twice as likely to experience admission to general hospitals than the general population. These include higher rates of and vulnerability to, specific health conditions, increasing longevity and the inevitable diseases of "old age", and the increasing complexity of health needs. It has also been projected that the number of people with learning disability will increase by 1% each year over the next 15 years and that the number of children and older adults with complex physical health needs will both be large areas of growth (DHSSPS 2005). Against this backdrop, it is clear that people with learning disabilities will increasingly require services within general hospitals.

People with Learning Disabilities and Contact with General Hospitals

It is the stated objective of Equal Lives (DHSSPS 2005) 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 7). This objective is underpinned by 14 recommendations for service developments. Furthermore, legislation over the past decade including the Human Rights Act (1998) and the Disability Discrimination Act (1995), has highlighted the legal requirement of health services ensuring equality, dignity and autonomy. These laws require that reasonable adjustments are made in all their services to ensure they do not 'unlawfully discriminate' against people with learning disabilities and include the provision of accessible information.

Contact with general hospitals for people with a learning disability is a frequent occurrence, with people with learning disabilities being twice as likely to use general hospital settings, compared to the rest of the population (NPSA 2004). Services required can range from emergency care provision, outpatient appointments and day procedures through to the need for surgical intervention and repeated lengthy admissions due to complex health needs.

Contact by people with learning disabilities with the general hospital service is most often for investigation to assist the diagnosis of learning disabilities, to monitor development and to investigate the degree of development delay in areas such as vision, hearing and mobility. People with learning disabilities also make use of hospital services for medical and surgical interventions and may also need swift access to emergency services, either as a result of the exacerbation of a chronic condition such as epilepsy, respiratory disease or a gastrointestinal disorder or, as the result of an accident (Barr 2004).

Challenges in Accessing and Using General Hospital Services

Despite the above policy objectives, access to primary and secondary healthcare services for people with learning disabilities has been a growing concern over the past decade. This has been reflected in a number of reports and inquiries. These reports include The National Patient Safety Agency (NPSA 2004) report "Understanding the patient safety issues for people with learning disabilities" which highlighted that the care of people with a learning disability in general hospital was a major safety concern.

Following on from "Death by Indifference" (Mencap 2007), a campaign document by Mencap, which chronicled the deaths of six people with learning disabilities in general hospital settings, The Michael Inquiry (DH 2008) highlighted the difficulties people with learning disabilities can often have in accessing a range of general health services. This inquiry made a number of recommendations for improvement. The Parliamentary and Health Ombudsman's 'Six Lives' Report (TSO 2009) instigated by "Death by Indifference", found evidence of major failings in the care of the six people with learning disabilities and concluded that on one occasion and possibly a second, the deaths of the people with learning disabilities were avoidable.

Within Northern Ireland a number of research projects into access to general health care such as "Promoting Access" (Barr 2004) and "Patient People" (SHSCC 2008), together with research specifically into access to Accident and Emergency services (Sowney & Barr 2007), have also identified major challenges in access to general healthcare for people with learning disabilities.

The findings of the above research reports and independent inquiries have, in particular, highlighted the need to improve the access to and safety within general hospitals. A number of persistent difficulties encountered by people with learning disabilities, their families and staff within general hospital services has been documented. These include:

People with learning disabilities

- Experience difficulty in understanding what was happening.
- Are provided with limited information.
- Do not feel involved in the discussions and decisions which have taken place.
- Have a lack of accessible information for people with learning disabilities.
- Experience confusion and fear arising from limited explanation and uncertainty about what is happening.
- Experience insufficient attention being given to making reasonable adjustments – e.g. addressing communication problems, difficulty in understanding and anxieties and preferences.

Families and carers of people with learning disabilities

- Often find their opinions and assessments ignored by healthcare professionals. They struggle to be accepted as effective partners in care.
- Experience long waiting times often in inappropriate environments, with limited information prior to and during contact with the hospital.
- Perceive poor quality of care in relation to hygiene, nutrition and maintenance of the safety of the person with learning disabilities.
- Identify that there are limited opportunities for meaningful activities and the environment results in the person with learning disabilities often becoming bored and restless.
- Experience limited forward notice of discharge, poor co-ordination of discharge and little or no support after discharge has been reported.
- Perceive the need to stay in hospital during the period of contact, with little effort made to facilitate their stay in the hospital or make it comfortable.
- Experience negative attitudes and stereotypes about people with learning disabilities. This can result in diagnostic overshadowing where doctors and others make mistaken assumptions about people with learning disabilities resulting in failure to diagnose accurately or the misinterpretation of symptoms.

Staff in general hospitals

- Have limited relevant information available about the person with learning disabilities on admission.
- Have limited knowledge, skills, experience and confidence in supporting people

with learning disabilities and are not familiar with what help they should provide or from whom to get expert advice.
- Experience difficulties in achieving informed consent and the required level of co-operation.
- Receive limited training in the needs of people with learning disabilities.
- Perceive partnership working and communication (between different agencies providing care, between services for different age groups, and across NHS primary, secondary and tertiary boundaries) as being poor in relation to services for people with learning disabilities.

(Barr 2004; Sowney & Barr 2006; Sowney & Barr 2007; DH 2008; SHSSC 2008; Backer et al 2009; TSO 2009)

Consequences of Ineffective Hospital Services For People with Learning Disabilities

The consequences of ineffective general hospital services for people with learning disabilities can be major for them as individuals, for their families and for service providers. The impact of the limitations of services has been described as distressing, at the very least, for people with learning disabilities and for some people these limitations have been reported as causing or contributing to their avoidable death, leaving family members with many unanswered questions. The findings of the Parliamentary and Health Services Ombudsman's investigation (TSO 2009) into the deaths of six people with learning disabilities identified failures in services such as:

- One death was avoidable and another was likely to have been avoidable.
- Distress and suffering for those involved.
- Unnecessary distress and suffering for the families of the aggrieved, in particular about those failings which occurred for disability related reasons.
- Distress at unanswered questions of what difference would have been made if there had been no service failure or maladministration. Would the person concerned have lived longer? Could there have been some improved enjoyment in the last period of their life?
- Distress compounded by poor complaint handling leaving questions unanswered.
- Distress arising from a failure to live up to human rights principles.

The Need for Effective Health Services

As noted earlier, there are clear policy and legislative requirements that require people with a learning disability to have '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' (DHSSPS 2005).

We recognise that a number of excellent initiatives have been developed in some Trusts to enhance the patient journey through general hospitals. However, these have mostly been project based and time limited with no dedicated and recurring resource to secure longevity. We trust that these guidelines are a helpful and informative step in assisting the process of improvement that is required.

STRUCTURE AND PURPOSE OF THE GUIDELINES

Within the GAIN document, there are 12 specific areas of improvement identified. These have been prioritised as the most pressing areas of need, based on a review of current published literature on this topic. The 12 priority areas for improvement focus on specific areas of the person's journey to and through the general hospital service (e.g. the journey through emergency care), transition processes (e.g. admission and discharge planning) and a number of clinical issues (e.g. nutrition and hydration). They are as follows:

- Attitudes and values;
- Communication;
- Training;
- Legal issues;
- Outpatients;
- The admission process and support during the hospital stay;
- Discharge planning;
- Emergency care;
- Support for carers;
- Nutrition and hydration;
- Pain;
- Children in hospital.

Each of these guidelines includes a best practice statement and a series of best practice indicators relevant to the particular area of improvement. It is important to recognise that the achievement of the best practice indicators is not solely the responsibility of staff working within general hospitals. It is apparent from reviewing the literature that improved quality and safety in the journey through general hospital settings will also be influenced by the recognition and implementation of the guidelines in partnership with local learning disability services, primary care, paid carers, family carers and managers of services. All have their part to play.

Many of the best practice initiatives that have been highlighted can be delivered through better individual care planning, together with improved communication and effective liaison within and between services. There will be some further resource implications in applying some of the best practice indicators and these may require more strategic planning. However, much progress can be made within existing resources through the actions of services and individual staff members, particularly in how they relate to people with learning disabilities and their families.

1. ATTITUDES AND VALUES

Best Practice Statement

Every individual with a learning disability using hospital services should have equitable access. Staff in a general hospital setting should demonstrate behaviours that are respectful, which include:

- Seeing the person not the disability;
- Ensuring that communication is sensitive to the needs and preferences of the person;
- Person centred care;
- Dignified, respectful and compassionate care;
- Non-judgemental attitudes.

Background

A central requirement in the provision of quality hospital care to people with a learning disability is underpinned by a philosophy that requires staff to recognise the human worth of a person with a learning disability and to adopt care practices that respect diversity. This creates new challenges for staff within hospital settings and one of the most important is to change attitudes towards patients with a learning disability.

Many of the issues that have been highlighted as poor practice are not resource dependent, but rather, they reflect attitudes that need to be changed. Improving the Patient and Client experience (DHSSPS 2008) identifies 5 overarching standards that will be central to the achievement of the best practice statements below. These include a focus being given to; respect, attitude, behaviour, communication and privacy/dignity.

Best Practice Indicators

1. **Equal does not mean the same:** Equality for a patient with a learning disability does not necessarily mean treating them in the same way. This may mean providing additional and alternative methods of support established with the patient and/or their families/carer in order to achieve a positive outcome.

2. **Autonomy:** All members of hospital staff should respect the wishes and choices of patients who have a learning disability. Patients must be actively involved in decisions regarding their care and steps should be taken to maximise their contribution to decision making (e.g. using pictures, information leaflets). This will require hospital staff to have a clear understanding of the law around capacity and consent.

3. **Contribution of Carers:** Families/carers have an important and unique contribution in the planning of the person's care and treatment. The importance of listening to the family/carers, recognising their particular knowledge of the patient with a learning disability and their ability to communicate with and understand responses, is significant. Often they are the only people who have a continuous relationship in the person's life; this contribution should be acknowledged, valued, listened to and acted upon.

4. **Advocacy:** Advocacy is the process whereby vulnerable people should be facilitated to have a voice and be heard. An advocate can be any "appropriate adult" for example, a family member/carer or friend or a link nurse within the hospital. It is important that the patient has a choice of someone they want and feel comfortable with. Identifying advocacy arrangements for the patient should be a core component of the assessment process in hospital, thereby promoting a person centred approach to care and treatment.

5. **See the person not the disability:** It is vital that health professionals look past the learning disability which can sometimes overshadow the presenting condition and may delay the investigation, diagnosis and treatment of their medical condition.

6. **Communication:** Establish, where possible, the patient's preferred method of communication. Staff should recognise the need to communicate directly with the patient with a learning disability at all times in the format they understand. Safe and person centred care is underpinned by effective and sensitive communication. "Clear communication means understanding and feeling understood." (DHSSPS 2008)

7. **Training:** All staff within general hospital services should receive training that increases their awareness of learning disability. Issues such as legal aspects, human rights, discrimination and the importance of good communication, attitudes and values should be included. In line with best practice, training on learning disability issues should also include people with learning disabilities and their family/carer as experts through experience.

8. **Don't make assumptions about the person's quality of life:** Hospital staff should ensure that they provide a balanced view of all treatment options available to patients with a learning disability. When major decisions around best interest need to be taken, there should be a clear understanding of the law and due regard must be given to the opinions and wishes of those closest to the patient. Everyday practice should place value on the quality of life of a patient with a learning disability.

Helpful Resources

http://www.dhsspsni.gov.uk/improving_the_patient_and_client_experience.pdf
DHSSPS Improving the Patient & Client Experience November 2008

http://www.dhsspsni.gov.uk/consent-guidepart4.pdf
DHSSPS Seeking Consent: Working with people with learning disabilities 2003

http://www.understandingindividualneeds.com/page.php?identity=health_and_wellbeing
Understanding Individual Needs, a web site that aims to help family, friends and professionals provide the best possible care and support to people with learning disabilities and ensuring they have a chance to lead a valued and fulfilling life.

http://www.mencap.org.uk/document.asp?id=6770
Mencap (2008) Getting it Right.

2. COMMUNICATION

Best Practice Statement

People with learning disabilities and their families/carers should experience effective and meaningful communication to support safe and person centred care.

Background

Safe and person centred care is underpinned by effective and sensitive communication. It is well established that the risk of harm increases if there is difficulty in communicating with the patient. Effective communication is multi-faceted and involves communication with the patient, communication with family/carers and communication between professional staff. Effective communication is supported by a number of key principles which include the understanding that:

- All people communicate using various means;
- People with learning disabilities communicate in a number of ways, both verbal and non-verbal;
- Behaviour is a means of communicating;
- The environment and how the person is feeling play a pivotal role in enhancing or limiting effective communication;
- It is the responsibility of hospital staff to understand, recognise, and take steps to address, the challenges of communication;
- A lack of clear and accessible information creates a barrier to accessing safe, effective and person centred healthcare;
- Effective communication may be facilitated by the involvement of family/ carers;
- Good listening skills and non-verbal communication are often the most important channels of communicating with people with learning disabilities.

Best Practice Indicators

1. An assessment of the person's preferred method of communication should be undertaken and staff should check if the patient has a document that highlights how they communicate (e.g. a health action plan, or hospital support plan. See helpful resources below).

2. The subsequent care plan should highlight the way(s) in which the person communicates specific needs/problems such as: hunger, thirst, toileting needs etc, or pain or distress.

3. Communication should always take place with the patient in the first instance, but staff should discuss (following consent/best interest decision) with family/ carers their role in facilitating communication with the patient. Staff should listen to and respect the advice/information given by the main carer, as they will have a detailed knowledge of the person with a learning disability.

4. Staff should adjust their verbal and non-verbal communication to meet the needs of the patient. Consider the following when communicating with patients who have a learning disability:
    - Address the person by their preferred name;
    - Speak slowly and don't shout;
    - Use very straightforward language and don't use medical jargon;.
    - Where appropriate the use of gestures, pictures, signs and symbols can help (see Hospital Communication Book in helpful resources section below);
    - The need for extra time to facilitate understanding. Make sure that the individual understands what you have said before moving on to the next topic;
    - Be aware that the patient may have additional hearing or visual impairments;
    - Pay attention to eye contact, body language, facial expression and contact via touch.

5. Staff should make use of and, where necessary, develop relevant resources, to assist in the provision of information. A range of easy read information sheets are available in a variety of formats to help patients understand what is going to happen during their stay in hospital. (See helpful resources section).

6. Staff should have regular training on communication skills, particularly centred on the challenges encountered when a patient has cognitive or other sensory impairments.

7. Trusts should develop a resource pack to support effective communication during the hospital journey. The Hospital Communication Book developed by The Learning Disability Partnership Board in Surrey, provides an excellent template for the development of such a resource.

8. Expressions of concern by individual patients or by family members or carers must be acknowledged and addressed immediately, using the proper and usual procedures. Complaints processes must be made accessible to patients who have learning disabilities and/or the family/carers. When concerns are addressed and openly discussed at an early stage, there is often no need for formal complaint processes.

9. Effective communication between professionals is central to the safe and effective delivery of care. This is particularly important at key stages during the hospital journey. For example, communication between nursing staff at handover, communication between consultants when a child is moving into adult services and communication between hospital and community professionals at discharge.

Helpful Resources

www.easyhealth.org.uk: a web site run by Generate, a charity working with people who have learning disabilities, provides very useful resources in terms of easy read information related to health issues.

www.easyhealth.org.uk/FileAccess.aspx?id=757: The Hospital Communication Book that is free to download and provides a comprehensive range of tools and advice to help people who have difficulties understanding and/or communicating get an equal service in hospital.

3. LEARNING DISABILITY TRAINING FOR GENERAL HOSPITAL STAFF

Best Practice Statement

Every individual with a learning disability has the right to receive care and services from knowledgeable, competent and skilled practitioners, in a timely, safe and caring environment that takes account of their specific needs. The training to support this care must be available to and accessed by all professional and non-professional staff who potentially deliver services to people with a learning disability, in the general hospital setting

Background

The health needs of people with learning disabilities are complex and their health care needs are often misunderstood by health care professionals. Evidence indicates that there is limited understanding and knowledge of the health problems they experience and the risk of harm to patients with a learning disability whilst in hospital (NPSA 2004).

A range of reports and inquiries has identified that training for staff in general hospital settings has been limited and patchy. This has resulted in uncertainty in providing safe, effective and appropriate care to people with learning disabilities when they require these services. Also, many staff still fail to understand their duties relating to the laws regarding disability, human rights and equality.

Respective professional Codes of Conduct and common law emphasise that it is every practitioner’s responsibility to be knowledgeable, competent and safe in providing treatment and services for all users of that service.

The knowledge, skills, attitudes and values of staff can improve through specific training on learning disability and the involvement of people with a learning disability in the development and delivery of such training is recommended within the Michael Report (HMSO 2008).

Best Practice Indicators

1. Academic and professional institutions that provide both undergraduate and post graduate clinical training should incorporate Learning Disability Awareness training within their curricula.

2. Learning Disability Awareness Training should be mandatory for all hospital staff who have direct patient contact in order to enhance their knowledge and skills in providing safe and effective care to patients with learning disabilities.

3. All new staff within Health and Social Care (HSC) services should receive appropriate training in learning disabilities, to include disability equality training as part of their Corporate Induction Programme.

4. The training of staff should be designed and delivered in partnership with people with learning disabilities and/or their carers.

5. The Learning Disability Awareness Training should be competence based and include the following core elements:

- An overview of learning disability - definitions and concepts;
- The health issues affecting people with learning disabilities and the barriers experienced when accessing generic health services;
- Service users' and carers' perspectives of equitable access, including personal experiences and proposals for best practice;
- Effective Communication;
- Legislative requirements such as consent and capacity, Equality of Opportunity, Disability Discrimination Act, Human Rights Act;
- Influential inquiries and reports - Death by Indifference (Mencap 2007), Patient People (SHSSC 2008);
- The provision of reasonable adjustments in the general hospital setting;
- How to access support from local learning disability services.

6. Additional training should be provided to key staff identified from within each clinical area. This would help facilitate them in the role of a Learning Disability Link Nurse to champion the needs of patients with a learning disability in that specific clinical area.

7. The Learning Disability Link Nurse training objectives should incorporate:
    - A greater awareness of the needs of patients with a learning disability;
    - An understanding of the risks of harm posed by being in the hospital environment and knowledge of how these risks can be managed;
    - An understanding of the difficulties facing patients with a learning disability and their carers when using hospital services;
    - Knowledge and skills in caring for patients who have a learning disability and the promotion of person centred care processes at ward level;
    - The development of local action plans to improve practice.

Helpful Resources

www.gain-ni.org the Southern Trust Learning Disability Awareness Training Pack and The Southern Trust link Nurse Programme.

http://www.dhsspsni.gov.uk/consent-guidepart4.pdf DHSSPS (2003) Seeking Consent: Working with People with Learning Disabilities

http://www.rcn.org.uk/data/assets/pdf_file/0004/78691/003024.pdf RCN (2006) Meeting the health needs of people with learning disabilities. Guidance for nursing staff. London, Royal College of Nursing.

4. LEGAL ISSUES IN THE DELIVERY OF CARE TO PEOPLE WITH A LEARNING DISABILITY

Best Practice Statement
Staff working in general hospitals will understand and apply the relevant legal and professional framework(s) and principles in the delivery of care to children and adults with a learning disability, ensuring that care is delivered in a safe, effective, personalised and non-discriminatory manner.

Background
From the review of the literature and the various reports/inquiries that have identified failings in care delivery to people with learning disabilities within general hospital settings, three areas of concern have been frequently highlighted:

a) Human Rights: People with a learning disability are not being afforded the same **human rights** as everyone else, in respect of being treated with dignity, equity, respect and consideration of autonomy. As a result, individuals with a learning disability have been subject to, and are at risk of, prolonged suffering and inappropriate care.

b) Equality of Opportunity and Reasonable Adjustments: The literature review has highlighted that there have been significant failures on the part of hospitals to provide equality of opportunity and to make adjustments that take account of a patient's level of cognitive or communication needs. Under Disability Discrimination legislation (DDA 1995) and Section 75 of the Northern Ireland Act (1998), public health service providers have a duty to make **reasonable adjustments** and to ensure that their services are fully accessible to people with a learning disability.

c) Consent and Capacity: A number of recent reports have suggested that health professionals working in general hospital settings do not understand the law in relation to **consent and capacity** as it applies to people with a learning disability. Consequently, treatment may be delayed or denied (Mencap 2007).

Best Practice Indicators

1. Staff working in general hospitals should receive specific training on the Disability Discrimination Act (1995), with particular emphasis given to the making of reasonable adjustments (at a practice, policy and organisational level). Human rights and consent training is also vital, with emphasis given on its application to people with learning disabilities. This training needs to be provided for healthcare staff working in both children and adult settings.

2. Reasonable adjustments should be considered not only in terms of physical barriers such as ramps and wheelchair access. Other practice, policy and procedural adjustments may require to be made such as:

   - Providing information in a format that is most likely to aid understanding;
   - The provision of longer appointments (e.g. in outpatients);
   - Effective communication with the individual and/or carers;
   - Appropriate mechanisms in place to identify pain and/or distress;
   - Appropriate complaint handling;
   - The level and extent of involvement of others such as family/carers/ advocate;
   - Identifying the reasonable adjustments that are required within the individual care/treatment plans.

3. For planned admissions, a pre-admission meeting involving the person with a learning disability and those close to them (family/carers/advocate) and perhaps local community learning disability services, will help to explore issues of consent, capacity, confidentiality and reasonable adjustments required.

4. Staff within general hospitals should make use of the skills and expertise of those who work in learning disability services and of advocates in situations where there is confusion/uncertainty.

5. Individuals with a learning disability should first and foremost be presumed to have capacity to make healthcare related decisions unless proven otherwise. Where there is doubt about capacity, this must be assessed by the professional responsible for the intervention. Family/carers should be involved in this process.

6. Where an individual is deemed **not** to have capacity, a best interests meeting should be convened to discuss specific decisions that need to be taken. However, in emergency/life threatening situations, health care staff can apply the doctrine of necessity which allows for immediate decision making that is deemed to be in the person's best interest.

7. Every hospital ward/clinical setting should have access to the document "Seeking Consent: Working with People with Learning Disabilities" (DHSSPS 2003).

8. For staff who work with children who have learning disabilities, the ward or clinical environment should have access to the document "Seeking Consent: Working with Children" (DHSSPS 2003).

9. With the agreement of the person with a learning disability, inform and advise carers (both paid and unpaid) fully in any discussions or decisions about care or treatment.

10. Treatment decisions must never be based on professional assumptions about the person's quality of life. This is of particular relevance if and when Do Not Resuscitate (DNR) decisions are being considered.

11. Do Not Resuscitate decisions must follow exactly the same legal and professional pathways for people with a learning disability as for everyone else.

Helpful Resources:

http://www.dhsspsni.gov.uk/consent-guidepart4.pdf
DHSSPS (2003) Seeking Consent: Working with People with Learning Disabilities

http://www.dhsspsni.gov.uk/consent-guidepart2.pdf
DHSSPS (2003) Seeking Consent: Working with Children

http://www.mencap.org.uk/document.asp?id=6770
Mencap (2008) Getting it Right.

5. PREPARING FOR AN OUTPATIENT APPOINTMENT

Best Practice Statement

All people with a learning disability who have an outpatient appointment at a general hospital will have an opportunity to be supported in preparing for this. Account should be taken of their abilities and needs, together with the implications of these to facilitate examination, treatment and care.

Background

The majority of contact patients have with hospitals is known about in advance and often relates to outpatient appointments for initial assessment, investigation or treatment.

It has been regularly noted within published literature that people with learning disabilities experience difficulties during their contact with general hospital services. This is often related to limited preparation that does not take full account of the abilities and needs of the patient and the implications of this for general hospital services.

Best Practice Indicators

1. When arranging an appointment the referrer should provide an indication of any additional support that may be required.

2. Managers of OPD Departments should take steps to facilitate contact for the person in advance of the appointment to discuss relevant details of the organisation and the nature of the appointment.

3. A structured approach in an agreed format (e.g. Traffic Light assessment or hospital passport. See helpful resources section) should be used to gather the information necessary to support the appointment. This should include key information about the patient's communication abilities, physical care needs, behaviour when distressed and other factors that may need to be considered in arranging the appointment time and the duration of the appointment.

4. Appointments should be planned to take account of the possibility that extra time may be required for explanation, discussion, providing reassurance and maintaining cooperation. Consideration should be given to offering the first or early clinic appointments.

5. All information about what to expect should be provided to people with learning disabilities and their family/carers in appropriate accessible formats, providing contact details for key staff who may be able to provide or organise support if required. Staff working in learning disability services will have a key role to play in the provision of this support.

6. Directions sent to the patient and signage within the hospital site should provide clear accessible information that will allow the patient to find the correct department easily.

7. There should be flexibility in the waiting arrangements that take account of the abilities and needs of the person. Specific consideration should be given to minimising distractions/noise, providing a quiet waiting area (e.g. a vacant consultation room), providing space to walk around, or leave the waiting area for short periods and be called back for their appointment.

8. The process of the appointment should be explained to the patient in plain language, outlining the sequence of events.

9. Throughout the appointment staff should monitor the person's level of comfort, anxiety, distress and understanding of what is happening.

10. At the end of the appointment staff should provide a clear explanation of the next steps in the process of care and should consider the need to liaise with local learning disability services.

Helpful Resources

http://www.nnldn.org.uk/a2a/: Access to Acute: a network for staff working with people with learning disabilities to support access to acute medical treatment.

www.easyhealth.org.uk: a web site run by Generate, a charity working with people who have learning disabilities, provides very useful resources in terms of easy read information related to health issues.

www.gain-ni.org The Traffic Light Assessment tool that has been developed by the Southern Trust provides important information about people with a learning disability to hospital staff.

www.healthpassport.co.uk/: This website provides a free downloadable version of a health passport used in Buckinghamshire. It was made by and for people with learning disabilities, and will help them access health appointments or when they need to go into hospital.

www.easyhealth.org.uk/FileAccess.aspx?id=2058 "Your next patient has a learning disability" can be accessed as an excellent resource leaflet for healthcare professionals who are unfamiliar with the needs of people with a learning disability.

http://www.hft.org.uk/Resources/Home%20Farm%20Trust/Family%20Carer%20Support/Documents/WorkingTogether.pdf Home Farm Trust (2008) Working together: easy steps to improving how people with a learning disability are supported when in hospital.

6. THE ADMISSION PROCESS AND SUPPORT DURING A HOSPITAL STAY

Best Practice Statement

When a person with a learning disability needs to be admitted to hospital, steps should be taken to prepare them, the hospital staff and the ward to ensure that they receive safe and effective care during their hospital stay.

Background

The changing patterns of morbidity among people with learning disabilities largely reflect the changes in the general population. Many people with learning disabilities also have additional health needs that may require an inpatient admission to hospital. The period of admission can range from a few hours (for day surgery) to several weeks. Often such admissions are known about in advance and this provides an opportunity for the preparation of people with learning disabilities and staff in the hospital to facilitate a safe journey.

Albeit that there are opportunities for planning admissions, there are some reported persistent limitations in the care of patients with learning disabilities which have resulted in unnecessary distress/suffering, discomfort and inequity and that may have had grave consequences for them.

Best Practice Indicators

1. People with a learning disability should have the opportunity for a pre admission meeting/ward visit prior to any planned admission. In this meeting, staff should make use of all available information, including any personalised health documents (Health passports, or Traffic Light assessments. See helpful resources section below) and the information available from family and members of the local learning disability services (day care/ community learning disability team).

2. In these planned circumstances local learning disability staff, in conjunction with family carers, should ensure that the relevant hospital staff are informed of key needs that the patient may have and hospital staff should ensure that

the clinical area is as prepared as possible for the person's admission. This preparatory phase should consider the possibility of the need for specific equipment to meet the person's needs.

3. There should be a coordinated approach in the handover of information to ward staff on admission and throughout the hospital stay. This may be provided by staff within local community learning disability service which should highlight the patient's abilities and needs and details of any additional support that may be required or any risks that may need to be managed. This information should direct subsequent care planning.

4. Each hospital ward should gather resources that can help when a person with a learning disability is admitted and ensure that this is accessible to all staff. For example, information regarding the contact points of local learning disability services, easy read information about the ward, the hospital and certain procedures such as blood tests and x-rays.

5. An up to date list of key contacts for staff in learning disability services should be available in all departments within general hospitals in order to facilitate prompt contact with these staff or services if required.

6. In wards that are frequently used by people with a learning disability, the hospital should identify staff to take on a link or champion role specific to the care of the person with a learning disability.

7. The individual patient should have an identified named nurse who is responsible for nursing care for the duration of their hospital stay.

8. Hospital staff should introduce themselves to the patient and their carers. People should be shown the ward layout, including toilet facilities, nurses' station and other important features of the ward. They should also be shown how to summon help if required.

9. The admission process and any planned investigation, treatment and care should be explained in plain language, outlining the sequence of events. This should include the opportunity to ask questions. A range of resources to help hospital staff provide understandable information can be accessed from the easy health website (see helpful resources section below).

10. All care should be provided in a manner consistent with the current Standards for Improving the Patient & Client Experience, ensuring the provision of respectful and dignified care (DHSSPS 2008).

11. Care should be taken to investigate fully the patient's presenting signs and symptoms and care should be taken to avoid the risk of "diagnostic overshadowing" which means not attributing the current condition to the presence of learning disabilities.

12. Medical and nursing care should be delivered on the basis of standard evidence, good practice and guidelines and in response to identified clinical need.

13. Hospital staff should continually explain procedures, changes in circumstances, medication etc. and ensure that the patient and carers understand what they have been told and have the opportunity to ask questions.

14. When the patient is required to undergo surgery particular activities should include a pre-operative visit by theatre/recovery nursing staff to the patient and their family at an agreed time. The theatre staff undertaking the pre-operative visit will discuss the following issues with the ward nursing staff, patient and main carer. If the patient is admitted on the day of the operation, the following information would need to be collected in another way:

    - The patient's previous experiences of anaesthesia and surgery;
    - How to manage the process of 'fasting';

- Any known behavioural patterns which may become evident when the patient recovers from the anaesthetic;
- The patient's communication needs;
- Whether the main carer wishes to accompany the patient to the anaesthetic room and/or to be present in the recovery room shortly after the patient recovers from the anaesthetic;
- Whether a ward nurse/carer needs to stay with the patient in the anaesthetic room until the patient is anaesthetised to provide continuity of care and support.

15. Hospital staff should consider the need for increased clinical observation of changes in the health condition of a patient with learning disabilities, given that some people may have less ability to articulate changes in how they are feeling. In such circumstances it is the responsibility of the ward staff to provide or commission additional resources to fulfil this need should it arise.

Helpful Resources

http://www.nnldn.org.uk/a2a/ : Access to Acute: a network for staff working with people with learning disabilities to support access to acute medical treatment.

www.easyhealth.org.uk: a web site run by Generate, a charity working with people who have learning disabilities, provides very useful resources in terms of easy read information related to health issues.

www.gain-ni.org The Traffic Light Assessment tool that has been developed by the Southern Trust provides important information about people with a learning disability to hospital staff.

www.healthpassport.co.uk/ : This website provides a free downloadable version of a health passport used in Buckinghamshire. It was made by and for people with learning disabilities, and will help them access health appointments or when they need to go into hospital.

www.easyhealth.org.uk/FileAccess.aspx?id=2058 "Your next patient has a learning disability" can be accessed as an excellent resource leaflet for healthcare professionals who are unfamiliar with the needs of people with a learning disability.

http://www.hft.org.uk/Resources/Home%20Farm%20Trust/Family%20Carer%20Support/Documents/WorkingTogether.pdf Home Farm Trust (2008) Working together: easy steps to improving how people with a learning disability are supported when in hospital.

http://www.rcn.org.uk/data/assets/pdf_file/0004/78691/003024.pdf
RCN (2006) Meeting the health needs of people with learning disabilities. Guidance for nursing staff. London, Royal College of Nursing.

Gates B, Barr O, (2009) Oxford Handbook of Learning and Intellectual Disability Nursing. London, Oxford University Press.

7. DISCHARGE PLANNING

Best Practice Statement

Individuals with a learning disability and where appropriate, their family/carers, will have a thorough and coordinated approach to discharge planning that meets their specific needs. Discharge planning will begin on the day of admission and will be evidenced within the patient's plan of care.

Background

People with learning disabilities access and avail of in-patient hospital services more often than the general population yet they are discharged from hospital more quickly. Evidence highlights that the discharge processes experienced by patients with a learning disability and their family often falls short of what would be regarded as good practice (Mencap 2007).

Issues such as untimely discharge (too early or delayed), inappropriate management of the process and discharge to unsafe environments are associated with a greater risk of harm to the individual (Mencap, 2007, Michael, 2008, Parliamentary and Health Service Ombudsman 2009).

Good discharge planning is known to reduce the length of hospital stay, reduce the likelihood of unplanned readmissions and achieve good patient outcomes and experiences (Shepperd et al 2004. See helpful resources below).

Best Practice Indicators

1. For planned admissions, the discharge process should be a partnership approach involving ward staff, the patient, their family/carer (where appropriate) and the Community Learning Disability Services and should commence prior to admission.

2. In the case of unplanned admissions, discharge planning should also be a partnership approach, beginning in the assessment period, then communicated and documented in the plan of care.

3. Where clinically appropriate, patients should be placed on the recognised care pathway related to their condition and a potential date of discharge should be communicated to the patient and family.

4. Staff also need to be aware of the potential distress that a patient with a learning disability (and particularly those with autism) may experience if an expectation of being discharged on a specific date does not become reality.

5. Staff should provide the patient with a clear explanation of the discharge process and respect the right of the patient to be actively involved in all decisions regarding their care.

6. As soon as is practically possible, a discharge planning meeting should be organised by the hospital staff, involving the patient and should include the family/carers and the relevant hospital and community/primary care staff to identify:

   - The potential date and time of discharge in order to plan the recommencing of normal daily activities, or recommended new care package;
   - Any potential difficulties the patient may experience on the day of discharge, such as waiting for lengthy periods in a discharge lounge;
   - The location and suitability of the environment to which the patient is being discharged;
   - Any other community/primary care staff who need to be informed of the patient's discharge;
   - The support that the patient and the family/carers may require to help the patient remain within their own home environment (wherever home is);
   - Where certain procedures need to be carried out in the home environment after discharge, competency based training for families or other essential carers should be initiated and overseen in hospital prior to discharge taking place.

NB. In some cases (e.g. following a short uncomplicated stay in hospital) it may be appropriate to proceed by telephone arrangement, particularly if convening a formal discharge planning meeting may delay discharge.

7. Prior to discharge, hospital staff should ensure that the patient and, where appropriate, the family/carers have been provided with clear, understandable information on the diagnosis, treatment given and any follow up treatment, appointments or specialist assessments that may be required. Of particular importance is information around medicines and the need to follow particular instructions such as bed rest, no lifting or any other requirements.

8. The above information must be communicated in a format that is understood. The easy health website (see helpful resources section) provides a wide range of information and booklets regarding health information and procedures that could be utilised.

9. Hospital staff should provide the patient with a contact number should they require further advice or information regarding their care following discharge.

10. Hospital staff should invite the patient, family/carers to provide evaluation or feedback of their experiences during their stay in hospital.

Helpful Resources

http://www.hft.org.uk/Resources/Home%20Farm%20Trust/Family%20Carer%20Support/Documents/WorkingTogether.pdf Home Farm Trust (2008) Working together: easy steps to improving how people with a learning disability are supported when in hospital.

Cochrane Database Systematic Review. Shepperd S, Parkes J, McClaren J, Phillips C.(2004) Discharge planning from hospital to home, 2004;(1):CD000313

8. ATTENDANCE AT EMERGENCY CARE SERVICES

Best Practice Standards

Every person with a learning disability using the emergency care service should receive timely, safe and effective care that takes account of their specific health needs.

Background

People with learning disabilities have greater health care needs than the general population, which increases their contact with the emergency care service.

Unlike planned admissions, these attendances often happen unexpectedly and the pace of work in this unfamiliar environment can increase anxiety and distress, adding to the patient's vulnerability. This fast moving environment creates the potential for limited information sharing and it is acknowledged that inadequate communication increases the risk of harm to the patient.

Best Practice Indicators

1. Staff within emergency care departments should develop a specific care pathway/protocol for identifying and caring for patients with a learning disability.

2. It is important for staff to assess the patient's needs and safety requirements. Fast tracking arrangements for all children and adults with a learning disability should be considered. Where fast tracking cannot be applied, emergency care staff should consider using quieter waiting areas.

3. Staff within emergency care departments should check with the patient or family/carer if they have documentation that identifies their individual method of communication and other relevant information that will be useful to support their assessment, investigation and provision of safe care (e.g. a health passport or traffic light assessment. See helpful resources section below).

4. During triage, staff need to allow extra time to assess the patient's needs in order to communicate effectively the proposed plan of care and to seek consent for examination, treatment and care. Where appropriate, support from the family/carers may be required to facilitate effective communication to help inform decision making.

5. Where possible, the same nurse should care for the patient throughout their journey within the emergency care department.

6. Staff should be aware that all behaviour is a means of communicating and that people with learning disabilities may express feelings of fear, anxiety and/or pain through odd or unusual behaviours.

7. All information on the diagnosis, investigations and care must be provided in a format that is understandable to the patient in the first instance. Health professionals can access a range of informative, easy to read leaflets that help explain procedures such as x-rays, blood tests and other procedures which are available from the easy health website (see helpful resources section below).

8. Careful consideration needs to be given to the admission/transfer/discharge planning, whether it is admission to a ward within the hospital, transfer to another hospital or discharge home. It is essential that time is taken to ensure that relevant information is passed on to other wards/departments/hospitals and healthcare professionals. Specific care needs to be taken to ensure that the individual and/or the carer(s) are familiar with and understand the discharge advice, including any medication, treatments or follow-up arrangements.

9. Staff within emergency care service should familiarise themselves with the contact information of their local Community Learning Disabilities Services. A referral can be made to the Community Learning Disabilities Services where the named nurse has any of the following concerns:
   a) the patient's safety;
   b) mental health and/or challenging behaviour;

c) the patient's ability to comprehend instructions or follow medication regimens.

10. If the individual is a frequent user of emergency care departments, planned preparatory work can be carried out by local Community Learning Disability Services to help emergency care staff understand specific needs when such circumstances arise.

Helpful Resources:
www.easyhealth.org.uk/FileAccess.aspx?id=757: A Hospital Communication Book that is free to download and provides a comprehensive range of tools and advice to help people who have difficulties understanding and/or communicating get an equal service in hospital.

www.gain-ni.org The Traffic Light Assessment tool that has been developed by the Southern Trust provides important information about people with a learning disability to hospital staff.

www.healthpassport.co.uk/ : This website provides a free downloadable version of a health passport used in Buckinghamshire. It was made by and for people with learning disabilities, and will help them access health appointments or when they need to go into hospital.

http:/www.mencap.org.uk/consent-guidepart4.pdf
Mencap (2008) Getting it Right.

http://www.dhsspsni.gov.uk/consent-guidepart4.pdf
DHSSPS (2003) *Seeking Consent: Working with People with Learning Disabilities*

http://www.dhsspsni.gov.uk/consent-guidepart2.pdf
DHSSPS (2003) *Seeking Consent: Working with Children*

9. SUPPORT FOR CARERS

Best Practice Statement
When a person with a learning disability is required to use the general hospital setting, carers should be engaged as healthcare partners throughout the pathway of care alongside, not instead of, healthcare staff.

Background
We know that people with a learning disability are vulnerable when they use hospital services and therefore, the involvement of those who are closest to the patient in their care will provide them with some reassurance during a time of anxiety, distress and upset. Family/carers can make a major contribution to the effectiveness of treatment and support by providing medical and other key information. For example, they are likely to possess skills that will enable the cooperation of the person to receive clinical or other nursing procedures. They can also identify risk areas in relation to aspects of care.

However, there can be a tendency for health care professionals to discount the involvement of carers and not to consult with them. Mencap (2007) highlighted this in their "Death by Indifference" report, suggesting that lack of involvement of families and carers can result in poor prognosis, wrong diagnosis and, potentially, avoidable deaths.

Alternatively, it is also too often expected or assumed by health care professionals that family/carers will continue their support and care delivery to people with learning disabilities when they go into hospital.

Family/carers and hospital staff should be working together, within the parameters of the patient's expressed wishes, his or her capacity and within the parameters of the law around consent and confidentiality, to achieve the best outcomes for patients with a learning disability.

If they decide to, the family/carers can also be involved in a range of helpful activities during the hospital stay such as, helping with meals, interpreting what the patient is trying to say and keeping the patient meaningfully occupied.

Best Practice Indicators

1. The crucial role that family/carers play is highlighted throughout all of the guidelines within this document and their involvement in the journey of care must be acknowledged, valued and listened to by hospital staff within the parameters of the patient's expressed wishes, his or her capacity and within the parameters of the law around consent and confidentiality. Doing so will help achieve the best outcomes for patients with a learning disability when they have to use general hospital services.

2. It is important that there is no expectation that family members and/or support staff from learning disability services are required to remain on the ward throughout the admission of a child or an adult with a learning disability and to provide direct care and support. First and foremost, the provision of direct care and support to the patient is the responsibility of the hospital staff. There will of course be circumstances when this additional support is provided (e.g. when the patient is a child, when the family carer chooses to do so, or in circumstances where the patient may have very specific needs related to their learning disabilities). It is therefore important that hospital staff establish at an early stage the role family / carers are able and willing to play in the provision of care and support during the patient's hospital stay.

3. All staff in the clinical area must be made aware of any additional support provided by family members or carers and should facilitate the presence of carers including agreed arrangements for visiting, breaks and refreshments. Staff should also remain alert to the fact that carers may also be concerned or worried about the patient.

4. The poor management of complaints has been highlighted in many of the reports and inquiries that have examined the care of people with learning disabilities in hospitals. When concerns are raised or complaints are made, steps should be taken immediately to make individual patients and/or their carers aware of the process and of their rights. Easy read information should be developed to support this. Effective and speedy investigation, empathetic and timely responses together with an apology where necessary, will help resolve concerns locally.

5. Family/carers could compile useful information in the form of a Traffic Light Assessment or Health Passport (see helpful resources), prior to admission. A copy of this can be held in the patient's medical record for future planned or unplanned admissions.

6. Family/carers have a key role to play in the process of effective communication and, in particular, in identifying or interpreting indicators of distress.

7. Hospital staff should also ask if independent advocacy is available for the patient who has a learning disability, particularly when there are difficult or contentious decisions. Although it is recognised that family and paid carers advocate strongly on behalf of the individual they provide care for, independent advocates have the potential to provide both the patient and their families and carers with additional support.

8. Family/carers and individuals with a learning disability themselves, should be involved in the provision of training to health care professionals.

9. Staff should consider whether family/carers would benefit from a carer's assessment.

Helpful Resources:
http://www.hft.org.uk/Resources/Home%20Farm%20Trust/Family%20Carer%20Support/Documents/WorkingTogether.pdf Home Farm Trust (2008) Working together: easy steps to improving how people with a learning disability are supported when in hospital.

www.carersuk.org Carers UK is the voice of carers, and aim to improve their lives by providing advice, information and support and campaigning for change.

www.mencap.org.uk/page.asp?id=1946 Mencap helps people with a learning disability, and those that care for them to have their voices heard in decisions that affect their lives. They may be able to provide local advisors to provide independent advocacy support in a range of circumstances.

10. EFFECTIVE NUTRITION AND HYDRATION

Best Practice Statement

People with a learning disability will receive high quality nutritional care based on individually assessed needs, which may be additional and more complex than that required by the general population. Quality nutritional care will involve appropriate screening, assessment, planning, monitoring, serving and, where necessary, safe practical help with eating and drinking.

Background

The importance and effects of meeting (or not meeting) the nutritional needs of patients with a learning disability in general hospital settings have been highlighted in many reports and inquiries mentioned in the literature review of this document. It is recognised that good nutrition and hydration in hospital are as crucial to well being and recovery as the medicines and other treatments that patients may receive.

The nutritional needs of people with a learning disability vary depending on the severity of their disabilities and sometimes associated conditions. The challenges of meeting nutritional needs can be exacerbated by communication difficulties whereby the individual is unable to articulate their need for food or fluids, likes and dislikes of food and fluid or feelings of nausea and pain. People with a learning disability may also be unable to exercise real choice as they may not have the means or the opportunity to do so. Due to their learning disability and sometimes additional communication difficulties, their opinion on menu choice is at risk of not being sought.

The incidence of eating, feeding and swallowing problems is higher in people with learning disabilities than in other population groups, with at least half of the adults with learning disabilities suffering from dysphagia. This has been highlighted as a major patient safety issue in the care provision to people with a learning disability (NPSA 2004). Therefore, if nutritional needs are not assessed and managed effectively, this can have detrimental health consequences, especially when the individual's health is already compromised. The following best practice indicators are reflective of the "Get your 10 a day: Standards for Patient Food in Hospital" (DHSSPS 2007).

Best Practice Indicators

1. Staff within the hospital setting should ascertain if the person being admitted has a traffic light assessment/health action plan (which is likely to include details of the need for nutritional health interventions/support to the person with a learning disability). There may also be useful information from the Speech and Language therapist within the Local Community Learning Disability Service.

2. Family/carers (both formal and informal) should be recognised as having expert knowledge of the person. This knowledge should be incorporated in the individual's care plan and used to plan and implement care while the patient is in a general hospital.

3. All children and adults admitted to general hospital should be screened to determine their nutritional status.

4. Following screening by nurses, patients who are identified as malnourished or at risk of malnutrition will be referred for and receive a nutritional assessment appropriate to their level of need.

5. Patients who require support with eating and drinking should be clearly identified and receive safe assistance as required.

6. Staff should strive to promote independence with individuals with a learning disability who require aids whilst feeding, such as plate guards and non slip mats.

7. Specialist assessment by a dietician, support and monitoring will be required for those individuals who suffer from swallowing difficulties and/or require to be fed via enteral/parenteral routes.

8. Patients who have a learning disability should have their food and/or fluid intake monitored and have this activity carried out in a way that is informative, accurate and up-to-date.

9. Additional support may be necessary to assist patients with menu choice. Pictorial menu cards for patients with a learning disability who are unable to understand written menus should be available so that the individual can be helped to choose. Use of personal place mats (highlighting likes or dislikes, risks, nutritional and nursing support) will be beneficial in assisting patient choice.

10. Meals should be presented in an appealing and appetising manner with minimal disruption at mealtimes.

Helpful Resources:

http://www.bapen.org.uk/pdfs/must/must_full.pdf Malnutrition Universal Screening Tool (MUST)

DHSSPS (2007) Get your 10 a day: The nursing care standards for patient food in hospital. DHSSPS. Belfast.

11. THE ASSESSMENT AND MANAGEMENT OF PAIN

Best Practice Statement
People with a learning disability will be thoroughly assessed for pain, with attention focused on both verbal and non-verbal indicators of pain and/or distress. Their pain should be fully investigated and treated according to clinical need.

Background
First and foremost, it is important to dispel the myth that people with a learning disability have a higher pain threshold than the general population. This is untrue and there is no evidence base for this suggestion.

Many people with a learning disability will be able to describe their pain. However, some people, particularly those with severe and profound disabilities, may have difficulty verbalising their pain and therefore will use other means to communicate their pain. These signs and symptoms can include:

- Increased agitation;
- Constant or frequent crying;
- Withdrawal;
- Fidgeting and/or repetitive movements;
- Self injurious behaviour;
- Tensing or body bracing to achieve a pain easing posture;
- Increased sweating, heart rate or breathing;
- Changes in eating or sleeping habits;
- Changes in frequency and type of seizures;
- Inappropriate laughing;
- Other behaviours that may challenge staff.

What is also important to consider are those indicators that may infer that the individual feels well and is not experiencing pain, distress or discomfort.
These can include:

- The individual feeling and looking relaxed;
- The individual shows pleasure;
- The individual is alert and responsive;
- The individual responds to the company of others;
- The individual is eating and sleeping well;
- The individual is cooperative to the requests of others.

Best Practice Indicators

1. Staff should be aware of possible indicators and expressions of pain that may be different than those usually seen and are specific to the individual receiving care. This includes non verbal expressions of pain and changes in behaviour.

2. For planned admissions, a pre-admission meeting involving the person with a learning disability and those close to them (family/carers/advocate) and perhaps local community learning disability services, will help to consider and explore the assessment and management of pain and distress.

3. In accurately assessing pain, the combined use of careful history taking, close observation of the individual, accurate interpretation of the communicative behaviour and clinical judgement is vital.

4. Staff should consider using the pictorial formats available in The Hospital Communication Book to help them identify the presence, location and severity of the pain being experienced (See helpful resources below).

5. Hospital staff should utilise the skills and expertise of specialist pain nurses if they are available. This will be particularly important in circumstances such as treatment for cancer related disorders or palliative care.

6. Staff should directly communicate with the patient and use straightforward questions about the presence of pain. They should be aware that the patient may need more time for responses.

7. Staff must communicate with family/carers well known to the patient, paying particular attention to baseline indicators of comfort and contentment, descriptions of changes in behaviour or previous/similar episodes.

8. Investigate indicators of pain and distress fully. Do not assume that the patient is refusing to co-operate. Take time to explain any plans for investigations, familiarise the patient with the environment and consider the assistance of family/carers during investigations.

9. Staff should rule out physical causes (such as pain and/or distress) for behaviour changes before attributing these changes to other reasons that may be associated with the learning disability or mental health issues.

10. Consider the need for regular analgesia rather than 'as necessary'. Be watchful for a response to analgesia, looking for indicators of well being or a reduction in pain indicators.

11. Be aware of possible undesired effects of medication and observe for these. Some people with learning disabilities may be more susceptible to undesired effects and some may find this difficult to articulate. Some people may be taking other medication for other conditions and it is vital that possible drug interactions are considered.

12. During the assessment process it is vital that staff consider that the person may be indicating distress as a consequence of other emotional factors rather than physical pain.

13. Pain assessment tools, using self report or observational methods and proxy reports have been designed for young children (Wong 1998) and for adults with a learning disability (e.g. Disability Distress Assessment Tool (DISDAT) and staff should give consideration as to their benefit and utilisation in each individual circumstance (See helpful resources below).

Helpful Resources

www.easyhealth.org.uk/FileAccess.aspx?id=757 A Hospital Communication Book that is free to download and specifically designed to help people who have difficulties understanding and/or communicating get an equal service in hospital.

www.disdat.co.uk/ A distress assessment tool designed by St. Oswald's hospice designed to help health professionals assess and identify distress indicators in people who have limited communication.

http://www.painknowledge.org/physiciantools/opioid_toolkit/components/Wong-Baker_Scale.pdfThe Wong-Baker FACES rating scale has been developed for children over 3 years and is particularly helpful for patients who may be cognitively impaired. It offers a visual description for those who do not have the communication skills to explain their symptoms and how they feel.

12. IMPROVING THE EXPERIENCE OF CHILDREN WITH A LEARNING DISABILITY

Best Practice Statement

Children and young people with a learning disability who use general hospitals will receive coordinated, safe, effective and child/family centred services that are age appropriate and based on assessed needs.

Background

All of the other guidelines within this document will apply to children as well as adults, but there is a need to highlight a number of important best practice indicators that have particular relevance for children. Although it is recognized within policy and legislation that children with a disability should always be regarded as children first, children with any type of significant disability may require a range of additional support beyond the type and amount required by children in general. Children with a learning disability use general hospitals on a similar basis as other children (e.g. accidents, tonsillectomy, heart defects etc), but will often be frequent users as a consequence of complex physical healthcare needs. In these circumstances, all staff involved should refer to the document, “Developing Services to Children and Young People with Complex Physical Healthcare Needs.” DHSSPS (2009).

The findings of the “Care at its Best” report (DHSSPS, 2005) should also be noted. This is the report of a Northern Ireland wide multidisciplinary inspection of the service for disabled children in hospital. The findings of the inspection informed the development of the document “Standards for the Care of Disabled Children in Hospital” (DHSSPS, 2010), which contains detailed standards covering key aspects of hospital care for disabled children regardless of the child’s disability or the hospital setting. The “Improving the Experience of Children with a Learning Disability” best practice statement which is presented here should therefore be read in conjunction with these more detailed standards.

Best Practice Indicators

1. If at all possible, a pre-admission assessment should be completed which will involve the child, parents/carers and relevant hospital and community staff.

Important information should be collated at this stage (e.g. using the traffic light assessment format – see helpful resources) as this will help hospital staff to understand and effectively meet the child's needs.

2. There should be fast tracking procedures in place for learning disabled children who use hospital frequently or who have difficulty coping with prolonged waiting periods, particularly in departments such as Emergency Care and Outpatients' Departments.

3. Every child or young person who has a learning disability must have an agreed discharge/transition plan that starts on admission and involves hospital personnel, community services (specialist and universal services), the child and the family.

4. There should be an identified community key worker who will be the point of contact with the hospital staff during the period of admission. This is most likely to be a community children's nurse or a community learning disability nurse. This individual should provide an appropriate level of community in-reach to the hospital.

5. Parents/carers should be acknowledged as having expert knowledge of their child's needs. The child and their parents/carers should be involved in all assessment, care planning and discharge processes. They should be encouraged to ask questions and should receive relevant information in a format they can understand.

6. Families should be supported to maintain contact with their child in hospital. There should also be an appropriate level of support and provision for family members who need, or wish, to be with their child during the night.

7. Children and young people who spend extended periods in hospital should have access to a range of special provisions such as free access to television, therapeutic leisure activities and/or music and art therapy.

8. Where extended periods in hospital occur, the child should be enabled to engage in appropriate play and social activity programmes during their stay and, where appropriate, there should be adequate education provision delivered by relevant educational and/or hospital staff.

9. Where certain procedures need to be carried out in the home environment after discharge, competency based training for families or other essential carers should be initiated and overseen in hospital prior to discharge taking place.

10. Particular attention needs to be given at particular transition points such as the transition from general hospital to community services and transitions between child to adult services within general hospitals. Key standards for these circumstances are available in the document "Integrated Care Pathway for Children and Young People with Complex Physical Healthcare Needs" DHSSPS (2009).

11. All staff working within paediatric wards should have access to relevant training on learning disability with specific emphasis given to, communication skills, co-morbidity such as epilepsy and autism and key patient safety issues such as medicines' management, child protection and identifying deterioration.

12. The contact numbers of local Community Learning Disability Services should be provided to all paediatric wards within general hospitals.

Helpful Resources

www.gain-ni.org The Traffic Light Assessment tool that has been developed by the Southern Trust provides important information about people with a learning disability to hospital staff.

http://www.dhsspsni.gov.uk/developing services to children_july_2009.pdf
Developing Services to Children and Young People with Complex Physical Healthcare Needs. (DHSSPS 2009).

http://www.dhsspsni.gov.uk/integrated care pathway-july09.pdf
Integrated Care Pathway for Children and Young People with Complex Physical Healthcare Needs DHSSPS (2009)

IMPLEMENTATION AND AUDIT

Implementation of the Guideline will be driven by HSC Trusts. Clearly there will be a range of variance across trusts and consequently the approach to implementation will differ from trust to trust. GAIN is therefore not prescriptive in this regard. However, we have included at Annex 1 an example of a possible implementation strategy for consideration.

We recommend that Audit Departments within HSC Trusts audit the implementation of the guideline and may wish to use a rolling programme to audit specific components of the guideline. However, it is also intended that there will be discussions between GAIN and RQIA to consider a specific regional review of the guidelines within the next 3 years.

REFERENCES

Avis, M. & Reardon, R. (2008). *Understanding the views of parents of children with special needs about the nursing care their child receives when in hospital: a qualitative study.* Journal of Child Health Care. .12 (1), 7-17.

Backer C, Chapman M, Mitchell D (2009) *Access to secondary healthcare for people with learning disabilities: A review of the literature.* Journal of Applied Research in Intellectual Disabilities. 22: 514-525

Barr O (2004) Promoting Access: *The experience of children and adults with learning disabilities and their families/carers who had contact with acute general hospitals in the WHSSB Area and the views of the nurses in these hospitals.* Western Health and Social Services Board.

Department of Health (2008) *Healthcare for All: Report of the independent inquiry into access to healthcare for people with learning disabilities.* Department of Health. London.

Department of Health, Social Services and Public Safety (2005) *Equal Lives.* Belfast: Department of Health, Social Services and Public Safety. Belfast

Department of Health, Social Services and Public Safety (2005) *Care at its Best, Report of the Multidisciplinary Inspection of Services for Disabled Children in Hospital.* Department of Health, Social Services and Public Safety. Belfast.

Department of Health, Social Services and Public Safety (2007) *Get your 10 a day: The nursing care standards for patient food in hospital.* Department of Health, Social Services and Public Safety. Belfast.

Department of Health, Social Services and Public Safety (2009) *Developing Services to Children and Young People with Complex Physical Healthcare Needs.* Department of Health, Social Services and Public Safety. Belfast

Department of Health, Social Services and Public Safety (2009) *Integrated Care Pathway for Children and Young People with Complex Physical Healthcare Needs.* Department of Health, Social Services and Public Safety, Belfast.

Department of Health, Social Services and Public Safety (2009) *Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Action Plan 2009-2011.* Department of Health, Social Services and Public Safety, Belfast.

Department of Health, Social Services and Public Safety (2010) *Standards for the Care of Disabled Children in Hospital.* Belfast: Department of Health, Social Services and Public Safety, Belfast .

Gates B Barr O, (2009) *Oxford Handbook of Learning and Intellectual Disability Nursing.,* Oxford University Press. London.

Gibbs, S.M., Brown, M.J., & Muir, W.J. (2008). *The experiences of adults with intellectual disabilities and their carers in general hospitals: a focus group study. 52, 12, 1061 – 1077.*

Mencap (2007) *Death by Indifference.* Mencap. London

National Patient Safety Agency (NPSA 2004) U*nderstanding the patient safety issues for people with learning disabilities.* NPSA. London.

Parliamentary and Health Services Ombudsman (2009) *Six Lives: the provision of public services to people with learning disabilities.* TSO London.

RCN (2006) *Meeting the health needs of people with learning disabilities. Guidance for nursing staff.* Royal College of Nursing. London.

Southern Health and Social Care Council (2008) Patient People: *Experiences of adults with a learning disability as hospital in-patients in Craigavon Area Hospital and Daisy Hill Hospital.* SHSCC. Lurgan.

Sowney, M., Barr, O. (2007) *The challenges for nurses within the accident and emergency care service communicating with and gaining valid consent from adults with intellectual disabilities.* Journal of Clinical Nursing. 16 (9): 1678-1686

Sowney, M., Barr, O. (2006) *Caring for adults with intellectual disabilities: perceived challenges for nurses in accident and emergency units.* Journal of Advanced Nursing. 55(1) 36-45

Wallace, R. & Beange, H. (2008). *On the need for a specialist service within the generic hospital setting for the adult patient with intellectual disability and physical health problems.* Journal of Intellectual & Developmental Disability. Vol.33 (4), P. 354 – 361.

Membership of the GAIN Sub-Group:
Caring for People with Learning Disabilities in General Hospital Settings

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Barry Rafferty
Lynette Carroll

Supported by:

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Sheila MComish	Services Manager

ANNEX 1

Example of a possible Implementation Strategy for consideration by HSC Trusts:

- An implementation steering group should be developed comprising senior hospital staff from nursing, medical and AHP backgrounds, senior staff from specialist community learning disability services, educational representation and service user and carer representation.

- Data analysis over the previous 5 years to identify within each general hospital the ‘hot spots’ where learning disabled clients are treated and cared for in order to localise the priority areas.

- There could be three strands to implementation which can be defined as follows; Corporate, Departmental and Individual which should include the 12 best practice statements outlined in the document.

- Operational action plans to be developed for each practice area within hospitals. Each action plan will be unique according to the particular area of practice There are areas within some general hospitals in N. Ireland that have developed successful strategies and these can be identified as examples of best practice and replicated elsewhere.

- Training programme to be developed considering existing programmes, for example, the existing equality and diversity training to incorporate the needs of the client group (see NB1 below).

- Development of a learning disability champions’ network within hospital departments. It may be necessary to share champions within departments (see NB2 below).

- A communication strategy between hospital and specialist learning disability services should be developed.

- Development of a resource file in each practice area.
- Consider investment in a specialist learning disability link practitioner.
- Development of health passports and communication passports for clients.
- Incorporating the GAIN guidelines into the in-house audit programme.

NB1 General induction is required for all staff regarding the specific needs of this client group. Equality and Diversity training which is part of the Trust's induction programme could be developed further to include the issues for learning disabled clients. Discussions should also commence with medical staff so that learning disability issues are identified within the medical induction programme.

NB2 Develop a learning disability champions' network for both children and adults within specific departments of the hospital such as emergency care, day procedures, out patients. Staff will be identified within departments and could also be utilised within other departments where the client group is less visible (e.g. in maternity wards). These staff will require further in-depth training.

Copies of this Audit report may be obtained by either contacting the GAIN Office or by logging on to the website

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HM Government

No health without mental health

A cross-government mental health outcomes strategy for people of all ages

DH INFORMATION READER BOX

Policy	Estates
HR/Workforce	Commissioning
Management	IM&T
Planning	Finance
Clinical	Social Care/Partnership Working

Document purpose	Policy
Gateway reference	14679
Title	No Health Without Mental Health: A Cross-Government Mental Health Outcomes Strategy for People of All Ages
Author	HMG/DH
Publication date	02 Feb 2011
Target audience	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, PCT Chairs, NHS Trust Board Chairs, Special HA CEs, Directors of HR, Directors of Finance, Allied Health Professionals, GPs, Communications Leads, Emergency Care Leads, Directors of Children's SSs, Prison, youth offending services plus wider criminal justice system, head teachers, employers, Royal Colleges
Circulation list	Directors of Nursing, Allied Health Professionals, GPs, Voluntary Organisations/ NDPBs, Patients, carers and service users
Description	This strategy sets out our ambition to mainstream mental health, and establish parity of esteem between services for people with mental and physical health problems. It shows how Government is working to improve the mental health and well being of the population, and get better outcomes for people with mental health problems. "No Health Without Mental Health" is accompanied by the following documents, published individually: • Delivering Better Mental Health Outcomes • The Economic Case for Improving Efficiency and Quality in Mental Health • Impact Assessment • Analysis of the Impact on Equality • Analysis of the Impact on Equality – Evidence base • Talking Therapies: A four year plan of action • Talking Therapies: Impact Assessment • Talking Therapies: Analysis of the Impact on Equality
Cross-reference	Delivering Better Mental Health Outcomes
Superseded docs	New Horizons: A Shared Vision for Mental Health
Action required	N/A
Timing	**N/A**
Contact details	Mental Health and Disability Department of Health 133–155, Waterloo Road London SE1 8UG www.dh.gov.uk/mentalhealthstrategy
For recipient's use	

No health without mental health

A cross-government mental health outcomes strategy for people of all ages

FOREWORD

The Prime Minister, David Cameron, and the Deputy Prime Minister, Nick Clegg, have made it clear that the Coalition Government's success will be measured by the nation's wellbeing, not just by the state of the economy. The public health White Paper *Healthy Lives, Healthy People*[1] is the first public health strategy to give equal weight to both mental and physical health. This Government recognises that our mental health is central to our quality of life, central to our economic success and interdependent with our success in improving education, training and employment outcomes and tackling some of the persistent problems that scar our society, from homelessness, violence and abuse, to drug use and crime.

The title of this strategy, *No Health Without Mental Health*, perfectly captures our ambitious aim to mainstream mental health in England. We are clear that we expect parity of esteem between mental and physical health services. The previous Government had expressed its intention to improve existing services for people with mental health problems and tackle the wider underlying causes of mental ill health. But it did not spell out how this would be delivered locally to give people better outcomes. Our approach aims to improve outcomes for all.

The challenges are enormous but the rewards of meeting them are great. At least one in four of us will experience a mental health problem at some point in our life, and around half of people with lifetime mental health problems experience their first symptoms by the age of 14. By promoting good mental health and intervening early, particularly in the crucial childhood and teenage years, we can help to prevent mental illness from developing and mitigate its effects when it does. So this strategy takes a life course approach, recognising that the foundations for lifelong wellbeing are already being laid down before birth, and that there is much we can do to protect and promote wellbeing and resilience through our early years, into adulthood and then on into a healthy old age. Only a sustained approach across the life course will equip us to meet the social, economic and environmental challenges we face and deliver the short- and long-term benefits we need.

The costs of mental health problems to the economy in England have recently been estimated at a massive £105 billion, and treatment costs are expected to double in the next 20 years. We simply cannot continue to allow costs to spiral upwards without ensuring that every pound of public money is being used efficiently.

But this is not just a question of statistics and money. Social inequality of all kinds contributes to mental ill health, and, in turn, mental ill health can result in further inequality – for example worse outcomes in employment and housing for people with mental health problems. When mental health services don't work, they can fail black and minority ethnic communities, young people who don't have stable family backgrounds and many others.

But when they work well, and work well with local public, private and voluntary and community sector agencies, they help people to overcome disadvantage and fulfil their true potential. That is why this mental health strategy is both a public mental health strategy and a strategy for social justice.

There are two powerful themes to our new approach. First, the Government must demonstrate its commitment and do the things that only the Government can do – but it cannot, on its own, deliver the ambitions in this strategy. We are drawing on commitments across Whitehall departments, employers, schools, local authorities and the voluntary and community sector. We all have a part to play to meet the social and economic challenge posed by mental ill health, and to improve the wellbeing of the population.

Second, power is moving away from the centre. The concept of the Big Society captures this shift, whereby citizens take more control over their lives and build more capable communities. It is particularly relevant to mental health. We want more decisions about mental health taken locally, with more flexibility for local people to make decisions based on local needs.

Our approach is based on the principles that the Government has laid down for its health reforms:

- putting people who use services at the heart of everything we do – 'No decision about me without me' is the governing principle. Care should be personalised to reflect people's needs, not those of the professional or the system. People should have access to the information and support they need to exercise choice of provider and treatment;
- focusing on measurable outcomes and the NICE Quality Standards that deliver them rather than top-down process targets; and
- empowering local organisations and practitioners to have the freedom to innovate and to drive improvements in services that deliver support of the highest quality for people of all ages, and all backgrounds and cultures.

The Government is investing around £400 million over the next four years to make a choice of psychological therapies available for those who need them in all parts of England, and is expanding provision for children and young people, older people, people with long-term physical health problems and those with severe mental illness.

We know the conditions that foster wellbeing. We know many of the factors that help people to recover from mental health problems and live the lives they want to lead. We know the interconnections between mental health, housing, employment and safe communities. This strategy builds on that knowledge, sets out the ambitions the Government shares with its partners and against which it will be judged, and invites others to join us in making better mental health for all a reality.

Rt Hon Andrew Lansley CBE MP
Secretary of State for Health

Paul Burstow MP
Minister of State for Care Services

CONTENTS

Annexes

Supporting documents (published separately)

- No Health Without Mental Health: Delivering better mental health outcomes for people of all ages
- No Health Without Mental Health: Impact Assessment
- No Health Without Mental Health: Analysis of the Impact on Equality
- No Health Without Mental Health: Analysis of the Impact on Equality (Evidence Base)
- No Health Without Mental Health: The economic case for improving efficiency and quality in mental health
- Talking Therapies: A four-year plan of action
- Talking Therapies: Impact Assessment
- Talking Therapies: Analysis of the Impact on Equality

1: INTRODUCTION AND EXECUTIVE SUMMARY

1.1 Mental health is everyone's business – individuals, families, employers, educators and communities all need to play their part. Good mental health and resilience are fundamental to our physical health, our relationships, our education, our training, our work and to achieving our potential. The Prime Minister and the Deputy Prime Minister have made it clear that success for the Coalition Government will be assessed not just on bringing about a healthy economy but also on the wellbeing of the whole population. Moreover, good mental health and wellbeing also bring wider social and economic benefits. But to realise these benefits, we all need to take action and be supported by the Government to do so. We all need to take responsibility for caring for our own mental health and that of others, and to challenge the blight of stigma and discrimination. Our objectives for employment, for education, for training, for safety and crime reduction, for reducing drug and alcohol dependence and homelessness cannot be achieved without improvements in mental health.

1.2 This mental health outcomes strategy looks to communities, as well as the state, to promote independence and choice, reflecting the recent vision for adult social care. It sets out how the Government, working with all sectors of the community and taking a life course approach, will:

- improve the mental health and wellbeing of the population and keep people well; and
- improve outcomes for people with mental health problems through high-quality services that are equally accessible to all.

1.3 This is a strategy for people of all ages, and throughout this document we will use the word 'people' to encompass infants, children, young people, working-age adults and older people.

1.4 While this strategy is specific to England, the challenges are common across the four countries of the United Kingdom. We will work closely with the Devolved Administrations in Northern Ireland, Scotland and Wales, recognising their particular and varying responsibilities. Each will consider the most appropriate arrangements to address the issues in ways that meet their own circumstances and needs.

Mental health is everyone's business – a call to action

1.5 A wide range of partner organisations, including user and carer representatives, providers, local government and government departments, have worked with the Department of Health to agree a set of shared objectives to improve mental health outcomes for individuals and the population as a whole. The six shared objectives are as follows:

(i) More people will have good mental health

More people of all ages and backgrounds will have better wellbeing and good mental health.

Fewer people will develop mental health problems – by starting well, developing well, working well, living well and ageing well.

(ii) More people with mental health problems will recover

More people who develop mental health problems will have a good quality of life – greater ability to manage their own lives, stronger social relationships, a greater sense of purpose, the skills they need for living and working, improved chances in education, better employment rates and a suitable and stable place to live.

(iii) More people with mental health problems will have good physical health

Fewer people with mental health problems will die prematurely, and more people with physical ill health will have better mental health.

(iv) More people will have a positive experience of care and support

Care and support, wherever it takes place, should offer access to timely, evidence-based interventions and approaches that give people the greatest choice and control over their own lives, in the least restrictive environment, and should ensure that people's human rights are protected.

(v) Fewer people will suffer avoidable harm

People receiving care and support should have confidence that the services they use are of the highest quality and at least as safe as any other public service.

(vi) Fewer people will experience stigma and discrimination

Public understanding of mental health will improve and, as a result, negative attitudes and behaviours to people with mental health problems will decrease.

Why do we need a new outcomes strategy for mental health?

1.6 If we are to build a healthier, more productive and fairer society in which we recognise difference, we have to build resilience, promote mental health and wellbeing, and challenge health inequalities. We need to prevent mental ill health, intervene early when it occurs, and improve the quality of life of people with mental health problems and their families.

1.7 Improved mental health and wellbeing is associated with a range of better outcomes for people of all ages and backgrounds. These include improved physical health and life expectancy, better educational achievement, increased skills, reduced health risk behaviours such as smoking and alcohol misuse, reduced risk of mental health problems and suicide, improved employment rates and productivity, reduced anti-social behaviour and criminality, and higher levels of social interaction and participation. These issues will be further explored in a suite of public mental health evidence reviews to be published shortly by the Department of Health.

1.8 Some mental health problems* are long lasting and can significantly affect the quality of people's lives, especially if they are not treated. Some people only experience a single episode of mental ill health. Others, who may have longer-standing problems, can enjoy a high quality of life and fulfilling careers. However, the personal, social and economic costs of mental ill health can be considerable. No other health area combines frequency of occurrence with persistence and breadth of impact to the same extent.[2] The stigma attached to mental ill health and the social barriers that surround it amplify its direct effects and damage the life chances of people with mental health problems.

1.9 There are indications that some problems are becoming more prevalent: for example, more young people have behavioural and emotional problems. The incidence of mental health problems – including in young people[3] – can increase in times of economic and employment uncertainty, as can the rate of suicide. The number of older people in our population is growing, with a corresponding increase in the number of those at risk of dementia and depression.[4]

*** Note on terms used in this strategy**
The phrase 'mental health problem' is used in this strategy as an umbrella term to describe the full range of diagnosable mental illnesses and disorders, including personality disorder. Mental health problems may be more or less common, may be acute or longer lasting and may vary in severity. They manifest themselves in different ways at different ages and may (for example in children and young people) present as behavioural problems. Some people object to the use of terms such as 'mental health problems' on the grounds that they medicalise ways of thinking and feeling and do not acknowledge the many factors that can prevent people from reaching their potential. We recognise these concerns and the stigma attached to mental ill health; however, there is no universally acceptable terminology that we can use as an alternative. A glossary including other frequently used terms can be found at Annex C.

Mental health problems – the statistics

At least one in four people will experience a mental health problem at some point in their life and one in six adults has a mental health problem at any one time.[5]

One in ten children aged between 5 and 16 years has a mental health problem, and many continue to have mental health problems into adulthood.[6]

Half of those with lifetime mental health problems first experience symptoms by the age of 14,[7] and three-quarters before their mid-20s.[8]

Self-harming in young people is not uncommon (10–13% of 15–16-year-olds have self-harmed).[9]

Almost half of all adults will experience at least one episode of depression during their lifetime.[10]

One in ten new mothers experiences postnatal depression.[11]

About one in 100 people has a severe mental health problem.

Some 60% of adults living in hostels have a personality disorder.[12]

Some 90% of all prisoners are estimated to have a diagnosable mental health problem (including personality disorder) and/or a substance misuse problem.

1.10 The quality of mental health care has improved significantly in recent years. Skilled and committed front-line staff have developed services that are internationally recognised. Two examples are the development of Early Intervention in Psychosis teams and the improved access to psychological therapies. The development of community-based services and the widespread integration of health and social care has meant that fewer people need inpatient care and the number of inpatients taking their own life has reduced.

1.11 However, much still needs to change, and the pace of that change has to be faster. In recent years there has been considerable top-down direction, with more emphasis on structures and processes rather than on outcomes. Little has been done to promote mental health and wellbeing. The development of functional teams has delivered very good care in some areas, but in others has led to the fragmentation of care and inefficiencies across services. Only recently has attention been paid to the importance of employment and housing in the recovery process. Progress has been uneven between different areas and across different conditions. Critically, not all groups have benefited equally from improvements – for example, many people from black and minority ethnic communities. Access to services is uneven and some people get no help at all. This contributes to health inequalities within and between groups with 'protected characteristics'.*

1.12 High-quality services depend on high-quality commissioning. Too often, commissioning of mental health services has not received the attention at senior

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* The 'protected characteristics' are set out in the Equality Act 2010 (see glossary at Annex C).

level that it requires. The focus has been on specifying what mental health providers should do, rather than on improving the quality of mental health commissioning – so, for example, new approaches to commissioning, such as Payment by Results, were not initially applied to mental health services.

The personal cost of mental health problems

1.13 Many mental health problems start early in life. Half of those with lifetime mental health problems first experience symptoms by the age of 14,[13] and three-quarters by their mid-20s.[14] Our most deprived communities have the poorest mental and physical health and wellbeing.[15] People with severe mental illnesses die on average 20 years earlier than the general population.[16] Improving the mental health and wellbeing of our population requires action across all sectors, locally and nationally. That is why this is a cross-government strategy.

1.14 Having mental health problems can be distressing to individuals, their families, friends and carers, and affects their local communities. It may also impact on all areas of people's lives. People with mental health problems often have fewer qualifications,[17] find it harder to both obtain and stay in work,[18] have lower incomes,[19] are more likely to be homeless[20] or insecurely housed, and are more likely to live in areas of high social deprivation.[21] They are more likely to have poor physical health. This is due in part to higher rates of health risk behaviours, such as smoking, and alcohol and substance misuse.[22] Some people with mental health problems have poor diets, may not be physically active and may be overweight, though the reasons for this are complex.

1.15 Mental health problems can also contribute to perpetuating cycles of inequality through generations.* However, early interventions, particularly with vulnerable children and young people, can improve lifetime health and wellbeing, prevent mental illness and reduce costs incurred by ill health, unemployment and crime.** Such interventions not only benefit the individual during their childhood and into adulthood, but also improve their capacity to parent, so their children in turn have a reduced risk of mental health problems and their consequences.

1.16 Adults of all ages can also benefit from age-appropriate practice and provision that promotes mental health and wellbeing and prevents mental illness. The Foresight Report on mental capital and wellbeing[23] set out a range of interventions, including simple actions that individuals can take to maintain their mental wellbeing. The Health and Safety Executive Management Standards for work-related stress[24] set out what employers can do to limit work-related stress and create a culture in which the risks of stress are reduced.

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* See the forthcoming public mental health evidence reviews for further information.

** See the forthcoming public mental health evidence reviews for further information.

The economic context

1.17 Mental ill health represents up to 23% of the total burden of ill health in the UK – the largest single cause of disability.[25] Nearly 11% of England's annual secondary care health budget is spent on mental health.[26] Estimates have suggested that the cost of treating mental health problems could double over the next 20 years.[27] More than £2 billion is spent annually on social care for people with mental health problems.[28]

1.18 Detailed estimates in 2003 put the costs of mental health problems in England at £77 billion, including costs of lost productivity and the wider impacts on wellbeing.[29] More recent estimates suggest that the costs may now be closer to £105 billion, of which around £30 billion is work related.[30] Sickness absence due to mental health problems costs the UK economy £8.4 billion a year and also results in £15.1 billion in reduced productivity.[31] Mental health problems add considerably to the costs of the education and criminal justice systems and homelessness services. They are also the most common reason for incapacity benefits claims – around 43% of the 2.6 million people on long-term health-related benefits have a mental or behavioural disorder as their primary condition.[32]

1.19 There are also the further, incalculable costs to the individual, their family and their community of lost potential and unrealised hopes and goals. The majority of mental health problems affect people early, interrupting their education and limiting their life chances.

1.20 We spend a great deal of public money on dealing with the consequences of mental health problems. Much of this money could be spent more efficiently, and many of the personal, social and economic costs could be prevented, by addressing the causes of these problems and identifying and treating them if, and as soon as, they arise. This strategy sets out what everyone needs to do to work towards this, and how it can be achieved.

A new approach

1.21 The Government has a new approach. We are committed to achieving change by putting more power into people's hands at a local level. We recognise that we can only achieve a stronger, more cohesive society and better mental health outcomes for everyone if people and communities are able to take more responsibility for their own wellbeing. We also know that taking the right action through early intervention can make a long-lasting difference to people's lives.

1.22 This mental health outcomes strategy will demonstrate how the Government's localised approach,[33] together with the reforms to health and other public services and action across all government departments, will deliver improvements by:

- lifting the burden of bureaucracy;
- empowering communities to do things their way;

- personalising the production and delivery of services and support;
- increasing local control of public finance;
- diversifying the supply of public services;
- opening up the Government to public scrutiny;
- promoting social action, social inclusion and human rights; and
- strengthening accountability to local people.

1.23 The Government has already published strategy documents and introduced legislation that will improve mental health outcomes. These include the Drug Strategy,[34] the cross-government strategy to tackle violence against women and girls,[35] responses to the call for views about the Department for Education's Green Paper on special educational needs and disability (the Green Paper will be published shortly),[36] and the Ministry of Justice's Green Paper.[37] It has also set out its ambition to turn around the lives of families with multiple and complex needs. Further details of other key government policies and strategies are described in Chapter 5 and summarised at Annex B.

1.24 The Department of Health has published a number of key policy documents setting out its proposals for reforms in the NHS, public health and adult social care. The NHS White Paper *Equity and Excellence: Liberating the NHS*[38] sets out the long-term vision for the NHS. *Healthy Lives, Healthy People* describes the strategy for public health in England. *A Vision for Adult Social Care: Capable communities and active citizens*[39] describes the direction for adult social care, focusing on personalised services and outcomes. Three outcomes frameworks have been developed alongside these strategies. Together they provide a coherent and comprehensive approach to tracking national progress against an agreed range of critical outcomes. Improving mental health outcomes is central to achieving the outcomes in all these three frameworks.

Outcomes strategies

1.25 This new approach to government means a different approach to direction setting – developing strategies to achieve outcomes. Outcomes strategies reject the top-down approach of the past. Instead, they focus on how people can best be empowered to lead the lives they want to lead and to keep themselves and their families healthy, to learn and be able to work in safe and resilient communities, and on how practitioners on the front line can best be supported to deliver what matters to service users within an ethos that maintains dignity and respect.

1.26 Such cross-cutting strategies recognise that the Government can achieve more in partnership with others than it can alone, and that services can achieve more through integrated, pathway working than they can from working in isolation from one another. This new approach builds on existing joint working across central government departments – and between the Government, local organisations, employers, service users and professional groups – by unlocking the creativity and innovation suppressed by a top-down approach.

1.27 In particular, outcomes strategies set out:

- the Government's work with the private and voluntary sectors to help shape policies, approaches and services that meet the needs of the population as a whole;
- the work across government nationally and locally that will help to deliver the broad range of public services and approaches that will meet the needs of the population and service users;
- the support that the Government will provide to these services to meet the outcomes for which they are accountable;
- the ways in which these services will be held to account for the outcomes they deliver – for example, through the public health, social care and NHS outcomes frameworks;
- our ambitions for the quality of services we want to make available to the population and service users, and to their families and carers, without exception; and
- the support, information and choices that will be offered to the public, service users, families and carers to enable them to make best use of these high-quality services.

1.28 This mental health outcomes strategy sets out how actions across government will help to deliver better mental health outcomes. It is more than a service improvement plan; it seeks to promote a transformation in public attitudes towards mental health.

1.29 It also sets out how care and support services (public health, adult social care, NHS healthcare and children's services) will contribute to the ambitions for progress, including improved mental health, that will be set by the Secretary of State for Health in each of the outcomes frameworks. The domains in all three outcomes frameworks already include proposed indicators that are relevant to mental health. These frameworks will evolve as further research is commissioned and better data on mental health outcomes become available. Being clear about our shared mental health objectives will help us to identify gaps in our information. This in turn will also inform the development of future indicators for the outcomes frameworks.

1.30 This mental health outcomes strategy is being published at a time of transition in local government, and health and social care. The Health and Social Care Bill proposes a shift of power away from the Department of Health towards people, communities and front-line staff, to give people greater control over the way in which services are designed and delivered to meet local needs. Where this document refers to the new structures, these are the Government's current intentions for those bodies, subject to Parliamentary approval.

1.31 A companion document, *No Health Without Mental Health: Delivering better mental health outcomes for people of all ages*, describes in greater detail how we will improve mental health outcomes using this new health infrastructure, what 'good' looks like in terms of outcomes, and the underpinning evidence base for interventions.

What will the strategy deliver?

1.32 As well as improving the mental health and wellbeing of the population, and services for people with mental health problems, this strategy will also help to deliver the best value for our society from the resources committed to mental health. By defining high-level objectives and providing evidence of effective practice, we will support local decision-making. Local services can then be designed to best meet the needs of local people. We will support high-quality local commissioning by the use of tools such as Payment by Results.

1.33 Specifically, we will:

- ensure that mental health is high on the Government's agenda by asking the Cabinet sub-Committee on Public Health to oversee the implementation of this strategy at national level, while the Cabinet Committee on Social Justice will tackle many of the underlying issues;
- make mental health a key priority for Public Health England, the new national public health service, and set out in this strategy why, at a local level, the new health and wellbeing boards and directors of public health will want to treat mental health as a priority;
- agree and use a new national measure of wellbeing;
- prioritise early intervention across all ages;
- take a life course approach, with objectives to improve outcomes for people of all ages;
- tackle health inequalities, and ensure equality across all protected characteristics, including race and age, in mental health services;
- challenge stigma by supporting and working actively with the Time to Change programme and others;
- invest around £400 million over four years to make a choice of psychological therapies available for those who need them in all parts of England, and expand provision for children and young people, older people and their carers, people with long-term physical health problems and those with severe mental illness;
- ensure that by 2014 people in contact with the criminal justice system will have improved access to mental health

services, as outlined in the Ministry of Justice Green Paper *Breaking the Cycle: Effective punishment, rehabilitation and sentencing of offenders*;

- commit funding from the Department of Health to ensure the best treatment possible for Service and ex-Service personnel;
- bring together a group of experts to identify non-legislative solutions to tackle low levels of body confidence;
- launch a set of 'recovery' pilots to test the key features of organisational practice to support the recovery of those using mental health services;
- publish, by April 2011, a series of reviews of evidence on improving public mental health;
- review the models of service and practice for both health visiting and school nursing;
- work with the Royal College of General Practitioners and the Royal College of Psychiatrists to agree advice and support for GP consortia to commission effective mental health services that are accessible to all, including the most disadvantaged and excluded;
- ensure that close working between the Department of Health and the Department for Work and Pensions supports mental health service providers to help people to enter into and return to work; and
- publish a new cross-government suicide prevention strategy this year.

1.34 Better mental health, mental wellbeing and better services must be better for all – whatever people's age, race, religion or belief, sex, sexual orientation, disability, marital or civil partnership, pregnancy or maternity, or gender reassignment status. These areas constitute the 'protected characteristics' or groups as set out in the Equality Act 2010. Chapter 6 sets out the Government's commitment to promoting equality and reducing inequalities in mental health. This commitment is embedded throughout the strategy and will be underpinned by an action plan covering the analysis of the impact on equality to support implementation, delivery and monitoring.

Central support for delivering the strategy

1.35 As set out in this strategy, the Government's reforms will provide the levers for delivering the services and outcomes that people with mental health problems want. Local action by health and social care professionals, freed to innovate and respond to the needs of service users, will be critical to achieving our outcomes.

1.36 At national level, the Cabinet sub-Committee on Public Health will oversee the implementation of the strategy and the Cabinet Committee on Social Justice will tackle many of the underlying issues.

We will also establish a Mental Health Strategy Ministerial Advisory Group of key stakeholders, including people with mental health problems and carers, to work in partnership to realise this strategy's aim to improve mental health outcomes for people of all ages.

1.37 During 2011 and 2012, while the NHS Commissioning Board and Public Health England are being established, this group will identify actions in the transitional year to deliver the mental health strategy. We will review the function of the Advisory Group from 2012 onwards once the NHS Commissioning Board and Public Health England have been established. However, we anticipate that it will become a focus for stakeholders to discuss how implementation of the strategy will take place and to review progress. It may advise on improved indicators for tracking progress against the mental health objectives that could be used locally, by the NHS Commissioning Board and potentially in future versions of outcomes frameworks.

1.38 Our approach in this strategy is to:

- set out clear, shared objectives for mental health;
- state what government departments will do to contribute to these objectives;
- set out how the three Department of Health outcomes frameworks – for public health, adult social care and the NHS – will require improvements in mental health outcomes;
- articulate how the improvements envisaged in those three frameworks will only be delivered through improvements in mental health;
- explain how these objectives can be achieved at both national and local levels and across agencies at a time of financial challenge; and
- show that positive change in people's lives is achievable.

2: GUIDING VALUES AND PRINCIPLES

2.1 This strategy is underpinned by the Coalition Government's three main guiding principles of:

- freedom;
- fairness; and
- responsibility.

Freedom – reaching our potential; personalisation and control

2.2 Wellbeing and good mental health are essential for each of us to reach our full potential. Mental health problems often start early in life and can have long-term and wide-ranging consequences – especially if they are not addressed. Prevention and early intervention can reduce and prevent these long-term adverse effects.

2.3 Having control over your life is associated with better physical and mental health. This also means ensuring that people with mental health problems are able to plan their own route to recovery,* supported by professional staff who:

- **help them identify and achieve the outcomes that matter to them**, including a suitable and stable place to live, educational opportunities, jobs and social contact; and
- **put them, and their families and carers, at the centre of their care** by listening to what they want, giving them information, involving them in planning and decision-making, treating them with dignity and respect, and enabling them to have choice and control over their lives and the services they receive.

Fairness – equality, justice and human rights

2.4 Any mental health outcomes strategy is a strategy for equality and human rights. This is because reducing inequality and promoting individuals' human rights reduces the risk of mental illness and promotes wellbeing. Moreover, there is clear evidence that mental health services do not always meet the needs of certain groups, particularly black and minority ethnic communities and older people. Many homeless people do not receive the support they need to overcome their mental health and substance misuse problems. The public sector duty in the Equality Act 2010 means that public bodies will need to be particularly mindful of how the inclusion and equitable treatment of all protected groups is incorporated, as public agencies produce, monitor and report on how they have met their equality objectives.

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* The term 'recovery' has developed a specific meaning in mental health. It has been defined as: 'A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life, even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life' (Anthony, 1993)[40] (see Glossary at Annex C). Although the term is not used in relation to children and young people, the underlying principles of the recovery approach are equally applicable.

2.5 The Government is committed to delivering equity of access to treatment, prevention and promotion interventions, as well as equality of experience and outcomes across all protected groups. This strategy also takes account of the impact of socio-economic status. It upholds the aims of the Equality Act 2010, protects and promotes human rights in accordance with UN and European Conventions, and supports compliance with the UN Convention on the Rights of Persons with Disabilities and the UN Convention on the Rights of the Child.

Responsibility – everyone playing their part and valuing relationships

2.6 Participation in meaningful activity is associated with improved self-esteem, wellbeing and mental health.[41] Good social relationships are associated with a range of positive outcomes, including better physical and mental health. Reducing isolation and building supportive social networks and relationships promotes good mental health and recovery as well as preventing mental health problems. Real improvement, however, will require acknowledging and addressing the differentials – both social and economic – that exist within and between protected groups.

2.7 Strong and cohesive communities provide an environment that fosters improved wellbeing and resilience. The Government has a critical role, but will only improve the wellbeing and mental health of individuals and the population if everyone plays their part. Professionals can provide tools for individuals to achieve better outcomes; families, friends, teachers, carers, employers and the wider community can motivate and support people to use them. Practitioners also have a key role in working with other services to identify and respond to wider individual and family needs.

Good practice example: the Brandon Centre for Counselling and Psychotherapy for Young People

The Brandon Centre in London is a charitable organisation that has existed for over 42 years. It offers confidential help and advice for 12–21-year-olds and its services include:

- **contraception and sexual health;**
- **counselling and psychotherapy, including cognitive behavioural approaches;**
- **parenting work; and**
- **Multisystemic Therapy (MST). The Centre ran the first randomised controlled trial of MST in the UK in partnership with Camden and Haringey Youth Offending Services, funded by the Tudor Trust, Atlantic Philanthropies and the Department of Health.**

The Brandon Centre has strong links with the local community, statutory services and academic institutions, and has a good track record in terms of engaging with young people whom other services find hard to reach.

3: IMPROVING OUTCOMES IN MENTAL HEALTH: OUR SHARED OBJECTIVES

3.1 We have worked with partner organisations and across government to develop **six shared high-level mental health objectives**. Together they describe a shared vision for mental health. We have also agreed a number of key areas for action under each objective. *No Health Without Mental Health: Delivering better mental health outcomes for people of all ages*, the companion document to this strategy, describes them in more detail.

3.2 This is the first time we have had a comprehensive set of shared objectives and priorities for mental health that cover better mental wellbeing in the population, better mental health care and support and better physical health for those with mental health problems, across the life course.

3.3 The Coalition Government is committed to a clear focus on, and a transparent approach to, outcomes across government, both nationally and locally. The shared mental health objectives and key areas for action will be delivered through the Government's approach to devolving power, co-ordinated cross-government action and the reformed health, adult social care and public health systems.

Outcome indicators

3.4 Some of these shared objectives relate directly to outcomes for which the Secretary of State for Health will hold the NHS Commissioning Board to account, and that are well supported by existing indicators in the NHS Outcomes Framework. Others are covered by proposed outcomes and indicators in the Public Health Outcomes Framework, on which the Government is consulting.[42] Nearly all these objectives are encapsulated in the proposed outcome descriptions in the consultation paper on the Adult Social Care Outcomes Framework.[43] The outcomes frameworks are discussed further in Chapter 5.

3.5 In some cases we will need to develop the indicators in these frameworks – to ensure that they are sufficiently sensitive and specific to demonstrate progress in mental health. The NHS Commissioning Board will set out more detailed measures as part of its Commissioning Outcomes Framework, which will incentivise GP consortia to secure improvements in outcomes. This strategy sets out examples of possible indicators and data sources that the NHS Commissioning Board could use in developing commissioning guidance for GP consortia.

3.6 The following paragraphs briefly describe the high-level objectives agreed with our partners, their relationship with the outcomes frameworks, and possible additional indicators that may be used to assess progress. More detailed analysis of available indicators for each objective (and any gaps) is discussed in the companion document *No Health Without Mental Health: Delivering better mental health outcomes for people of all ages*.

The six mental health objectives

3.7 The **first agreed objective** is:

(i) More people will have good mental health

More people of all ages and backgrounds will have better wellbeing and good mental health.

Fewer people will develop mental health problems – by starting well, developing well, working well, living well and ageing well.

3.8 To achieve this, we need to:

- improve the mental wellbeing of individuals, families and the population in general;
- ensure that fewer people of all ages and backgrounds develop mental health problems; and
- continue to work to reduce the national suicide rate.

3.9 This objective links directly to the Prime Minister's announcement on measuring the wellbeing of the nation.

3.10 A good start in life and positive parenting promote good mental health, wellbeing and resilience to adversity throughout life. Many mental health problems start early and are associated with a number of known risk factors, including inequality. We know that employment is generally good for people's mental health and that being out of work carries an increased risk of mental health problems. Poor mental health and wellbeing are associated with a broad range of adverse outcomes, including high levels of health risk behaviours such as smoking, and alcohol and drug misuse, and experience of violence and abuse. Conversely, access to green spaces is associated with better mental health.[44]

3.11 Risk behaviours may become ways of dealing with emotional and other problems. As young people move through their teenage years and make the transition into adulthood, our aim is to strengthen their ability to take control of their lives and relationships, and to help to increase their self-esteem and emotional resilience.

3.12 Young people's ideas about body image and what looks good are strongly influenced by fashion and friends; and body image is linked to self-esteem. Eating disorders have a peak age of onset in adolescence. For more information see *No Health Without Mental Health: Delivering better mental health outcomes for people of all ages*.

3.13 Problems may be many and interrelated – for example, a third of families with multiple problems have at least one family member who has a mental health problem. A whole-family approach that addresses mental health together with other issues, such as domestic violence or alcohol misuse, has been shown to reduce the risks associated with mental health problems. As life expectancy increases, it is critical that healthy life expectancy also increases. We know more about which interventions and factors work to improve mental wellbeing and prevent problems developing. By focusing on the prevention of mental health problems and the promotion of mental wellbeing, we can significantly improve outcomes for individuals and increase the resilience of the population, while reducing costs. This is explained in more detail in *No Health Without Mental Health: Delivering better mental health outcomes for people of all ages* and in the forthcoming public mental health evidence reviews.

3.14 The agreed key areas for action are:

- ensuring a good start in life; and
- reducing the social and other determinants of mental ill health across all ages, and the inequalities that can both cause and be the result of mental health problems including, for example, social isolation, particularly among older people.

How will we know if we are making progress on the key areas for action?

3.15 A great deal of work has been done on developing measures for mental health and wellbeing to show whether or not we are making tangible improvements in mental health outcomes and tackling the determinants of mental ill health. There is still more to do to establish a definitive set of measures, but a range of potential indicators is set out below:

- The Office for National Statistics (ONS) is consulting on national measures of wellbeing.
- A well-evidenced example for measuring adult mental wellbeing is the Warwick-Edinburgh Mental Wellbeing Scale, which has been included in the Health Survey for England.
- The Psychiatric Morbidity Surveys can be used to estimate the rates of mental health problems in adults and children and changes over time.
- All 21 of the proposed indicators on tackling the wider determinants of ill health in the Public Health Outcomes Framework will have a positive effect on mental health, and there is also a range of appropriate indicators in other domains, including self-reported wellbeing.

3.16 The **second agreed objective** is:

(ii) More people with mental health problems will recover

More people who develop mental health problems will have a good quality of life – greater ability to manage their own lives, stronger social relationships, a greater sense of purpose, the skills they need for living and working, improved chances in education, better employment rates and a suitable and stable place to live.

3.17 Mental health problems are common, and vary in their nature and severity and in their impact on an individual over time. They can be long lasting and can have a serious impact on quality of life for individuals and their families and carers. Again, we know a great deal about what works to improve outcomes; for example, we know that by intervening early we can prevent problems becoming more serious and long lasting. Different approaches are required for children, young people, adults of working age, adults with complex multiple needs and older people, but some approaches are effective in reducing distress and improving functioning across all protected groups. For instance, the principles of the recovery approach, which emphasises the importance of good relationships, education, employment and purpose alongside reductions in clinical symptoms, can apply to all age groups. Mental health services also need to recognise that it might be necessary to respond differently to some groups, particularly those with protected characteristics, in order to achieve similar outcomes.

3.18 The principles of high-quality care are widely accepted and described in the companion document.

3.19 The key areas for action, agreed with partner organisations, are:

- to identify mental health problems and intervene early across all age groups;
- to ensure equity of access for all groups, including the most disadvantaged and excluded (for example people who are sleeping rough) to high-quality, appropriate, comprehensive services;
- to build care and support around outcomes that matter to individuals to enable them to live the lives they want to live, including good relationships, purpose, education, housing and employment;
- to offer people age- and developmentally-appropriate information, and a choice of high-quality evidence and/or good practice-based interventions, including psychological therapies;
- to ensure that all people with severe mental health problems receive high-quality care and treatment in the least restrictive environment, in all settings; and
- to work with the whole family, using whole-family assessment and support plans where appropriate.

3.20 In partnership with the Centre for Mental Health and the NHS Confederation, the Department of Health will launch a set of 'recovery' pilots to test the key features of organisational practice to support the recovery of those using mental health services. Initial results will be published within the next 12 months.

How will we know if we are making progress on the key areas for action?

3.21 The proposed Adult Social Care Outcomes Framework describes key aspects of recovery. In particular, it recognises that:

- earlier diagnosis and intervention mean that people are less dependent on intensive services; and
- when people become ill, recovery takes place in the most appropriate setting and enables people to regain their wellbeing and independence.

3.22 In the NHS Outcomes Framework, recovery is the focus of Domain 3: 'Helping people to recover from episodes of ill health or following injury'. This domain reflects the importance of helping people to recover as quickly and as fully as possible from ill health or injury. In this context, the term is used principally to mean clinical recovery.

3.23 Recovery is also captured within Domain 2: 'Enhancing quality of life for people with long-term conditions', through the two improvement areas: 'Enhancing quality of life for people with mental illness – employment of people with mental illness' and 'Enhancing the quality of life for carers'.

3.24 However, these indicators do not cover the full spectrum of positive mental health outcomes. The problem is not that outcome measures have not been defined – in fact, many outcome measures are in use by different provider organisations – but few are standardised and routinely collected across mental health services. We will work with partner organisations to agree and develop an appropriate number of key outcome measures and ways to collect them. This will provide the information that individuals need to make real choices between services and approaches, and will allow commissioners and providers to benchmark their services against one another. We will need to give consideration to the collection of more robust and systematic data in relation to all groups.

3.25 In the meantime, the Mental Health Minimum Dataset allows the collection of a number of mainly proxy indicators that are relevant to this outcome. It also includes the Health of the Nation Outcome Scales (HoNOS) for people with severe mental illness. Improving Access to Psychological Therapies (IAPT) services record individual service user outcomes, using standard assessment tools on each contact. The NHS Commissioning Board may wish to use indicators from these datasets in assessing whether or not progress is being made on improving mental health outcomes. Examples include:

- the proportion of people discharged from inpatient care who are followed up within seven days. There is good evidence to suggest that this seven-day period is critical in helping to prevent suicide and self-harm following discharge;
- community survival time from inpatient discharge to readmission in mental health services; and
- employment and education status for people using IAPT services.

3.26 The **third agreed objective** is:

(iii) More people with mental health problems will have good physical health

Fewer people with mental health problems will die prematurely, and more people with physical ill health will have better mental health.

3.27 Having a mental health problem increases the risk of physical ill health. Depression increases the risk of mortality by 50%[45] and doubles the risk of coronary heart disease in adults.[46] People with mental health problems such as schizophrenia or bipolar disorder die on average 16–25 years sooner than the general population.[47] They have higher rates of respiratory, cardiovascular and infectious disease and of obesity, abnormal lipid levels and diabetes.[48] They are also less likely to benefit from mainstream screening and public health programmes.

3.28 Increased smoking is responsible for most of the excess mortality of people with severe mental health problems. Adults with mental health problems, including those who misuse alcohol or drugs, smoke 42% of all the tobacco used in England.[49] Many wish to stop smoking, and can do so with appropriate support. Over 40% of children who smoke have conduct and emotional disorders.[50] This is particularly important as most smoking starts before adulthood. People with mental health problems need good access to services aimed at improving health (for example, stop smoking services).

3.29 Mental health problems such as depression are also much more common in people with physical illness. Having both physical and mental health problems delays recovery from both.[51] Children with a long-term physical illness are twice as likely to suffer from emotional or conduct disorder problems.[52] People with one long-term condition are two to three times more likely to develop depression than the rest of the population. People with three or more conditions are seven times more likely to have depression.[53] Adults with both physical and mental health problems are much less likely to be in employment.

3.30 The agreed key areas for action are:

- that fewer people with mental health problems should have poor physical health;

- that fewer people with mental health problems should die prematurely; and
- that fewer people with physical ill health, including those with long-term conditions and medically unexplained symptoms, should have mental health problems.

How will we know if we are making progress on the key areas for action?

3.31 The proposed Public Health Outcomes Framework suggests indicators on:

- the mortality rate of people with mental illness (Domain 5); in Domain 1 of the NHS Outcomes Framework a related indicator is 'Under 75 mortality rate in people with serious mental illness';
- the rate of hospital admissions for alcohol-related harm (Domain 3);
- the smoking rate of people with serious mental illness (Domain 4);
- the uptake of national screening programmes (Domain 4);
- the suicide rate (Domain 5);
- the infant mortality rate (Domain 5); and
- mortality rates from cardiovascular disease and chronic respiratory diseases (Domain 5), which will be influenced by improvements in the mental health of people with these conditions.

3.32 The **fourth agreed objective** is:

(iv) More people will have a positive experience of care and support

Care and support, wherever it takes place, should offer access to timely, evidence-based interventions and approaches that give people the greatest choice and control over their own lives, in the least restrictive environment, and should ensure that people's human rights are protected.

3.33 Putting individuals at the heart of services is a key driver of the Government's *Equity and Excellence: Liberating the NHS* reforms. This means that people can, as far as possible, control and manage their own support so that it matches their needs and aspirations. People feel they are respected as equal partners, and know what choices are available to them and who to contact when they need help.

3.34 Those who provide support will respect the human rights of each individual. They will respect their privacy and dignity and ensure that support is sensitive to their particular needs.

3.35 A truly individually focused approach such as this necessarily results in non-discriminatory services for people of all backgrounds.

3.36 In the case of mental health, these principles are particularly important: being in control of your own life helps you to recover. They are equally important to families and carers. However, many mental health service users and their families and carers still report their frustration that mental health services fall a long way short of these principles.

3.37 Sometimes treatment has to be delivered under the Mental Health Act, without a person's consent. Where that happens, it is important that the guiding principles in the Act's Code of Practice are applied. These include the least restriction principle: 'People taking action without a patient's consent must attempt to keep to a minimum the restrictions they impose on the patient's liberty, having regard to the purpose for which the restrictions are imposed'.

3.38 Care and support should be appropriate for the age and developmental stage of children and young people, adults of all ages and all protected groups. Careful planning of the transfer of care between services will prevent arbitrary discontinuities in care as people reach key transition ages. Services can improve transitions, including from child and adolescent mental health services (CAMHS) into adult mental health services, or back to primary care, by:

- planning for transition early, listening to young people and improving their self-efficacy;
- providing appropriate and accessible information and advice so that young people can exercise choice effectively and participate in decisions about which adult and other services they receive; and
- focusing on outcomes and improving joint commissioning, to promote flexible services based on developmental needs.

3.39 The Department of Health is funding a programme to support services to improve the experience of young people who are moving from CAMHS to adult services. The programme is being run in partnership by the National Mental Health Development Unit (NMHDU), the National CAMHS Support Service and the Social Care Institute for Excellence. The programme will produce a series of practical tools and learning resources and will run to November 2011.

3.40 It is particularly important to maintain a positive experience of care and support for people who are treated under the Mental Health Act. In 2009/10 there was an increase in detentions under the Mental Health Act. The early use of community treatment orders was also much greater than predicted. The Government will ensure that the use of detention and community treatment orders is kept properly under review, so that action can be taken if necessary to change the law.

3.41 The agreed key areas for action are:

- that services should be designed around the needs of individuals, ensuring appropriate, effective transition between services when necessary, without discriminatory, professional, organisation or location barriers getting in the way; and
- that, wherever possible, services should listen to and involve carers and others with a valid interest and provide them with information about a patient's care, to ensure that confidentiality does not become an obstacle to delivering safe services. Best practice on involving families and carers is included in Chapter 4.

How will we know if we are making progress on the key areas for action?

3.42 Historically, it has generally been difficult to measure the experience of people with mental illness, and that is why in the NHS Outcomes Framework we have selected an improvement area that will capture the experiences of this group. In Domain 4, 'Ensuring that people have a positive experience of care', the improvement area 'Improving experience of healthcare for people with mental illness' has been included, and will use the indicator 'Patient experience of community mental health services'. The mental health services indicator will draw on the new Community Mental Health Services Survey. We will also review the previously developed Mental Health Inpatient Survey to assess the extent to which it is possible to include it in future frameworks.

3.43 This is also an area where the NHS Commissioning Board is likely to need to identify more detailed progress indicators.

3.44 The Adult Social Care Outcomes Framework comprehensively covers this area. It proposes a range of indicators for service user experience of care and support, including the proportion of people who use 'self-directed support'. Some of these types of indicator may well be helpful to the NHS Commissioning Board, particularly once the pilots of personal health budgets are evaluated and the learning put into practice. One proposed measure also takes account of the proportion of carers who report that they have been included or consulted in discussions about the person they care for.

3.45 All outcome indicators will be disaggregated by protected characteristics to support monitoring and delivery of services. It will take time to do this, in order to comply with the law, but it is particularly important in terms of mental health services. The NHS Commissioning Board will have a particular responsibility for reducing inequalities in healthcare. The Board, and local health and wellbeing boards, will want to take account of more detailed indicators, such as the use of detention in some minority ethnic groups and the under-representation of Asian women receiving support from mental health services.

3.46 The **fifth agreed objective** is:

(v) Fewer people will suffer avoidable harm

People receiving care and support should have confidence that the services they use are of the highest quality and at least as safe as any other public service.

3.47 Improved services will result in:

- fewer people suffering avoidable harm from the care and support they receive;
- fewer people harming themselves;
- fewer people suffering harm from people with mental health problems; and
- further progress on safeguarding children, young people and vulnerable adults.

3.48 Particular issues of concern have been human rights, and safety and dignity in inpatient facilities, including secure environments. There are a number of initiatives, such as the Acute Care Declaration,[54] which will continue to improve the quality and safety of the inpatient environment.

3.49 Self-harming in young people is not uncommon (10–13% of 15–16-year-olds have self-harmed in their lifetime).[55] Only a fraction of cases are seen in hospital settings; therefore, all those in contact with young people should be aware of how, and when, to refer somebody on for further assessment and support.

3.50 A continuing focus on reducing suicide rates in people with mental health problems and the population in general will be critical. A new cross-government suicide prevention strategy will be published this year outlining shared objectives for action.

3.51 The vast majority of people with mental health problems pose no danger to themselves or anyone else. Those with severe mental illness are more likely to be the victims of violence than its perpetrators. In a few cases a person's mental disorder does raise the risk of them harming someone else. This raised risk is mainly due to people with serious antisocial personality disorder, substance dependence and hazardous drinking.

3.52 Although serious incidents involving a person with severe mental illness are extremely rare, we recognise the public's concerns about safety. However, we also recognise that such serious incidents can add significantly to the stigma surrounding mental health. Mental health services must play their part in reducing and managing risks of harm, through their own interventions where they are best placed to intervene, or by helping other agencies to do what they are best placed to do. The companion document *No Health Without Mental Health: Delivering better mental health outcomes for people of all ages* has further details on the management of risk, appropriate sharing of information and learning lessons from serious incidents.

How will we know if we are making progress on the key areas for action?

3.53 The relevant proposed outcome statements for adult social care are as follows:

- everyone enjoys physical safety and feels secure;
- people are free from physical and emotional abuse, harassment, neglect and self-harm; and
- people are protected as far as possible from avoidable deaths, disease and injury.

3.54 There are relevant indicators within several of the NHS Outcomes Framework domains. For example, the overarching indicators of Domain 5 are:

- patient safety incident reporting;
- severity of harm; and
- number of similar incidents.

3.55 This is likely to be an area where the NHS Commissioning Board will wish to identify or commission more detailed indicators of progress – for example, the rate of suicide among people in contact with NHS-commissioned services. Collection of suicide rates by ethnicity is also important. The ONS collects annual statistics on suicides and undetermined deaths. The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness will publish its latest analysis of the findings of independent investigations into patient homicides later this year.

3.56 The **sixth agreed objective** is:

(vi) Fewer people will experience stigma and discrimination

Public understanding of mental health will improve and, as a result, negative attitudes and behaviours to people with mental health problems will decrease.

3.57 Stigma and experiences of discrimination continue to affect significant numbers of people with mental health problems. This discrimination is damaging, unlawful and costly – for individuals, their families and carers, organisations, communities and society as a whole. People with mental health problems have worse life chances than other people. Part of this is the direct effect of the condition, but a very large part is due to stigma and discrimination, driven by ignorance and fear, and some people's negative attitudes towards them. Stigma can also affect the attitudes and behaviours of clinicians, including mental health clinicians, and commissioners. It can:

- stop people from seeking help;
- keep people isolated, and therefore unable to engage in ordinary life, including activities that would improve their wellbeing;
- mean that support services have low expectations of people with mental health problems, for example their ability to hold down a challenging job; and

- stop people working, being educated, realising their potential and taking part in society.

3.58 Tackling stigma and discrimination and promoting human rights are at the heart of this strategy. A number of mental health trusts currently undertake local anti-stigma and discrimination activities, gaining additional benefit by encouraging service user involvement, thereby aiding their recovery.

3.59 However, to shift public attitudes substantially requires a major and sustained social movement. Recognising that children and young people can suffer greatly from the effects of mental health stigma, YoungMinds has prioritised combating stigma in their Children and Young People's Manifesto. Comic Relief and the Big Lottery have funded a major anti-stigma campaign, Time to Change, led by Mind and Rethink and evaluated by the Institute of Psychiatry. The programme of 35 projects aims to inspire people to work together to end the discrimination surrounding mental health. The programme is backed by international evidence on what works, and has at its heart people with direct experience of mental health problems. Supporters include individuals, employers, sports organisations and NHS trusts.

3.60 The Government knows, from discussions with voluntary and private sector organisations, that there is an appetite for an even more ambitious programme. We will give this social movement our full support. We commit to supporting and working actively with Time to Change and other partners on reducing stigma for people of all ages and backgrounds.

3.61 The Government also plays a role in this by leading by example and providing the legislative framework. For example, the Equality Act 2010 sets out the responsibilities of organisations and employers towards disabled people, including people with mental health problems.

3.62 The agreed priority is that fewer people will suffer from stigma and discrimination as a result of negative attitudes and behaviours towards people with mental health problems – to be achieved by improving public attitudes and reducing the institutionalised discrimination inherent in many organisations, including support services.

How will we know if we are making progress on the key areas for action?

3.63 Time to Change already uses a range of indicators to measure change in attitudes to mental health in the general population, among employers and in the experience of people with mental health problems. We will work with Time to Change to agree the best ways to assess improvements over the lifetime of this strategy, including an annual attitudes survey.

4: IMPROVING OUTCOMES IN MENTAL HEALTH: WHAT DOES THIS MEAN FOR INDIVIDUALS, FAMILIES AND COMMUNITIES?

4.1 The mental health and resilience of individuals, families and communities is fundamental to building a fair and free society which protects people's human and civil rights. This can only be achieved if we all work together in partnership. We know that, being in control of our own lives, good relationships, purposeful activities and participation in our communities improve our mental health.

4.2 The Coalition Government is committed to putting more power into people's hands at local level. It recognises that only when people and communities have more power and better information and can take more responsibility will we achieve a stronger society, better mental health, and fairness and opportunity for all. Local communities, local people and local services are best placed to solve the problems they face.

4.3 This does not mean that the Government has no responsibility. The Government as a whole must take a lead and will be held to account for improving mental health outcomes. But the Government alone cannot deliver the changes necessary to achieve our shared objectives.

4.4 Every one of us has something to contribute to improving individual and population mental health. As individuals we can get involved in different ways:

- we can all challenge stigma and discrimination, and negative attitudes by trying to gain a better understanding of mental health problems;
- we can ensure that we look after our own mental health better; and
- we can get more directly involved in local decision-making, volunteering and local action, including in schools and colleges, at work and in our local communities.

4.5 Users of services will increasingly be able to take decisions about their own healthcare. They and their carers may wish to become involved in the planning and design of local services.

Information

4.6 To become involved and to take control in all these ways, people need the right information at the right time. Some people also need support and advocacy. This section of the chapter describes our proposals on information reform. In chapter five we set out the new framework for advocacy in the health and social care systems.

4.7 The Government will continue to work with partner organisations to explore different ways – in the media and elsewhere – of improving public understanding of mental health issues. This will include working with Time to Change (see paragraph 3.60), the national campaign to raise awareness of mental health issues and change attitudes and behaviours towards people with mental health problems.

4.8 The Government will ensure that the population as a whole knows what it can do to improve its wellbeing and stay healthy. There are many things individuals can do to improve their own mental health; for example, drinking within safe limits, taking regular exercise and participating in meaningful activities, such as arts and sports activities and experiencing the natural environment.*

4.9 A model that individuals can adopt to improve their personal wellbeing was recommended in the Foresight report on mental capital and wellbeing.[56] The 'Five ways to wellbeing' suggests that people:

- **connect** – with the people around them, family, friends and neighbours;
- **be active** – go for a walk or a run, do the gardening, play a game;
- **take notice** – be curious and aware of the world around them;
- **keep learning** – learn a new recipe or a new language, set themselves a challenge; and
- **give** – do something nice for someone else, volunteer, join a community group.

4.10 Already, some local mental health trusts and some public health bodies, particularly in the north west, are publicising what people can do to improve their wellbeing in this way. This will be a clear responsibility for Public Health England, and local government, through health and wellbeing boards, will wish to develop this further. The Government has published advice to local commissioners on the evidence base for wellbeing.[57] The Department of Health is also working with the Department for Business, Innovation and Skills on a project to better understand some of the effective ways of communicating these key messages about mental wellbeing to the public.

4.11 *Equity and Excellence: Liberating the NHS* stated: 'Information, combined with the right support, is the key to better care, better outcomes and reduced costs.' It sets out a number of important changes that will ensure timely, high-quality information is available to patients, families, carers and the public so that they can make decisions about their own mental health care and support, and about mental health services.

4.12 Tailored, age- and developmentally-appropriate methods are needed to communicate with children and young people so that they can understand their mental health problems and the choices they have about their treatment and care.

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* The natural environment is defined as the green open spaces in and around towns and cities as well as the wider countryside and coastline.

This will include evidence-based care and services – for example, communicating through play – especially for very young children. Better communication across all groups is key. These include people from minority ethnic groups; people for whom English is a second or third language and who may not read English; and people who use British Sign Language. Third parties will be encouraged to provide information on services. Web-based support groups and charities could have an important role to play in sharing information with families about services.

Greater choice, control and personalisation

4.13 Personalisation is about respecting a person's human rights, dignity and autonomy, and their right to shape and determine the way they lead their life. Personalised support and services are designed for the purposes of independence, wellbeing and dignity. Every person who receives support should have choice and control, regardless of the care setting. This is of critical importance for people with mental health problems – we know that feeling in control leads to better mental health. Choice and control over their support services is just as important for ex-offenders, drug users and other socially excluded groups.

4.14 The NHS White Paper *Equity and Excellence: Liberating the NHS* sets out a range of proposals for giving people greater choice and control over their care and treatment. These were described in more detail in the consultation document *Liberating the NHS: Greater choice and control* published in October 2010. The proposals envisage that greater choice and control over care and treatment, choice of 'any willing provider' wherever relevant, and choice of treatment and healthcare provider will become the reality in the vast majority of NHS-funded services by no later than 2013/14. These proposals will extend to mental health service users choices that are not currently available.

4.15 People of any age who have complex health needs may require highly specialist help. Some people need to be treated without their consent under the Mental Health Act. It can be difficult to offer full choice – for example, choice of provider – in these circumstances, but it remains important for clinicians to engage people in decisions about personalising their treatment, and to respect their wishes as far as possible, not least because this can make a real difference to outcomes.

4.16 Choice is fundamentally about the objectives and circumstances of treatment and care. It is just as relevant for children and young people as for adults. It includes treatment in age- and developmentally-appropriate settings, care designed to enable children and young people to be at home with their families as much as possible, and treatment that enables them to lead as normal a life as possible, at school or college and with their friends.

4.17 Personalised care budgets for long-term conditions are a way of giving people more choice and control over how their support needs are met. *A Vision for Adult Social Care: Capable communities and active citizens* makes it clear that personal budgets, preferably delivered as direct payments, should be provided to all eligible people. The proposed partnership agreement, *Think Local, Act Personal*,[58] recommends how councils, health bodies and providers need to work more efficiently to personalise and integrate service delivery across health and adult social care. It is important that any personalised support package also considers the needs of children in the family to prevent them from taking on inappropriate caring roles.

4.18 The Government is piloting the application of the same principles when devising personal health budgets, including mental health budgets. Other pilot sites are developing plans to include people who are in transition from children to adult services in their programmes. The learning from the evaluation, due to report in October 2012, will inform the further roll-out of personal health budgets. Currently the law restricts direct payments of NHS funds to individuals, except in the pilot sites. The Government will take steps to extend as much as possible the availability of personal health budgets to people with mental health problems.

4.19 The Department of Health will be publishing its response to the consultation *Liberating the NHS: Greater choice and control* in the next few months. It will include detailed proposals for extending choice and control in mental health services.

The Mental Health Helplines Partnership (mhhp) is an example of collaborative working to provide a more professional, comprehensive and personalised service for people. Fifty helpline mental health providers including national, local and specialist helplines have come together to ensure anyone needing emotional and psychological support or experiencing distress can access help 24/7, 365 days a year. Innovative telephone, text, email and web chat services are available for individuals, carers and staff, whether volunteer or paid, at www.mhhp.org.uk.

Families and carers

4.20 Families and carers, young and old, often receive limited help and too often report that they are ignored by health professionals on grounds that they need to protect the confidentiality, and respect the wishes, of the service user. However, families and carers, including children, have detailed knowledge and insight and are often best placed to advise health and social care professionals about what may help or hinder the recovery of the person for whom they are caring. If they are well supported and listened to, families and carers can continue their caring responsibilities for longer and participate fully in decisions about services and how care is delivered. The refreshed carers strategy, *Recognised, Valued And Supported: Next steps for the Carers Strategy*,[59] sets out the actions that the Government will take over the next four years to ensure the best possible outcomes for carers and those they support. These include:

- supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset, both in designing local care provision and in planning individual care packages;
- enabling those with caring responsibilities to fulfil their educational and employment potential;
- personalised support, both for carers and for those they support, enabling them to have a family and community life; and
- supporting carers so that they remain mentally and physically well.

4.21 In partnership with the Princess Royal Trust for Carers and the Acute Care Declaration consortium, the Government has published *The Triangle of Care – Carers included: A guide to best practice in acute mental health care*,[60] which sets out six key elements of good practice for mental health professionals working with carers:

- carers and the essential role they play are identified at first contact or as soon as possible thereafter;
- staff are 'carer aware' and trained in carer engagement strategies;
- policy and practice protocols on confidentiality and sharing information are in place;
- defined post(s) responsible for carers are in place;
- a carer introduction to the service and staff is available, with a relevant range of information across the acute care pathway; and
- a range of carer support services is available.

Citizens, and neighbourhood and community groups

4.22 The Big Society agenda outlined by the Prime Minister will support better mental health outcomes. The three key strands are:

- **community empowerment** – creating neighbourhoods and communities that are in control and that pull together to shape the world around them. The evidence shows that cohesive communities foster better mental health;[61,62]
- **public service reform** – getting away from central control; giving front-line staff and practitioners more freedoms and opening up public services to new providers, in particular to charities, social enterprises, mutuals and co-operatives. We know that much innovation in services has come from front-line staff working with service users in order to develop new approaches to better meet their needs; and
- **social action** – fostering and supporting social action, social inclusion and volunteering. Evidence shows that volunteering can improve wellbeing.[63,64,65]

4.23 Empowered and cohesive communities foster better mental health. Services that offer greater choice and control and increased social action all have a positive impact on mental wellbeing.

4.24 *A Vision for Social Care: Capable communities and active citizens* sets out the Government's commitment to strengthening local communities and promoting active citizenship. Published in parallel, *Practical Approaches to Improving the Lives of Disabled and Older People through Building Stronger Communities*[66] sets out why building strong and resilient communities is a key component of social care transformation, outlines approaches currently being developed by councils with their public sector and community partners, and directs readers to useful materials. The new Big Society Bank will help to create an environment in which innovative approaches to social investment and social enterprise will flourish by working with intermediary organisations to increase access to finance for charities, social enterprises and other civil society organisations. The Government is keen to progress this project as quickly as possible, subject to the availability of dormant account funds.

4.25 *Equity and Excellence: Liberating the NHS* set out plans for local HealthWatch to ensure that views and feedback from carers, patients and service users are an integral part of local commissioning of health and social care services. Developed from Local Involvement Networks, these local HealthWatch bodies will be funded by and accountable to local authorities. Through their national body, HealthWatch England, they will report, independent of local authorities, any concerns about the quality of local health or care services. Local authorities will be able to commission local HealthWatch or other independent organisations to provide advocacy and support for people with mental health problems and their families and carers so that they can make decisions and choices about local services. This will be in addition to statutory independent mental health advocates who are already available to most patients detained under the Mental Health Act and to patients on supervised community treatment or under guardianship. The advocate's role is to help these patients to understand how the Act applies to them, and what rights it gives them, and to support them in exercising those rights.

4.26 Furthermore, local voluntary and community organisations can draw on the wealth of experience of their local communities in meeting the needs of groups they work with, including those groups most excluded and/or experiencing poor mental health. Some of these organisations have experience of helping people to manage their own mental health better in the community – including through peer support services, user-led self-help groups, mentoring and befriending, and time-banking schemes, which enable service users to be both providers and recipients of support. Well-managed and well-supported volunteering opportunities can help people to develop the skills and confidence to play a more active role in their own wellbeing and their community, and to influence the shape and scope of local services. Innovative approaches aimed at involving service users and the wider community can also help to break down barriers and reduce stigma. The Department of Health is currently refreshing its strategic vision for volunteering, which will highlight the benefits of volunteering and encourage good practice in promoting and supporting this more broadly.

Employers and businesses

4.27 Being employed is generally good for people's mental health and wellbeing. The workplace provides an important opportunity for people to build resilience, develop social networks and develop their own mental capital. Employers in all sectors, including the public sector, can play an important role in supporting the health and wellbeing of their staff by providing healthy workplaces which support their employees' mental health and wellbeing.[67]

4.28 As one of the world's largest employers, the NHS is leading the way through, for example, implementing Dr Steven Boorman's recommendations[68] for improving staff health and wellbeing. Across government we will look to take lessons from this work in the NHS.

4.29 Employment can also be an important part of many people's recovery from mental health problems. People with mental health problems can and do work – and supporting them to do so can save employers significant costs relating to staff turnover, under-performance and untapped potential. There is a considerable amount of guidance available on what employers can do to help people with mental health problems to stay in, return to and perform well at work. Often these are simple, low-cost and common-sense interventions.[69] A new Responsibility Deal with industry, non-governmental and other organisations will look at ways of improving the health and wellbeing of the working-age population to enable people to remain in employment and return to work after a period of illness.

Front-line staff across all sectors

4.30 The Government is committed to ensuring that front-line staff are enabled to put innovative ideas into practice. Ensuring that front-line staff are knowledgeable, motivated and supported is one of the keys to closing the gap between central policy ambitions and the changes that actually take place.

4.31 By adopting a personalised approach, practitioners working with service users, carers and their families will deliver the outcomes that individuals want. Improving co-ordination between mental health, drugs and alcohol services is important for improving outcomes for the most vulnerable and excluded. Practitioners may also be involved in the design, planning and delivery of high-quality services and are well placed to help GPs and local partners in commissioning high-quality services.

4.32 Practitioners across all services and sectors can do a great deal to tackle negative attitudes to people with mental health problems and to challenge stigma and discrimination. However, they have to be valued in return. The Government wants staff in mental health services to be valued as much as all other NHS staff. Including mental health awareness in all core front-line professional training – in sectors such as healthcare, teaching, public health and the police – would help to ensure that all mental health problems are identified early across all health and social care settings, and appropriately managed. Increasingly, service providers are working in multi-professional teams, allowing a whole-family assessment and support plan to be put in place.

Improving information and communication through the use of technology

4.33 Information technology and telecommunications have the potential to offer new ways of working with people at risk of, or suffering from, mental health problems. While younger people are often the first to embrace new technologies, such approaches are likely to be equally applicable to adults of any age. Technology can be used to share information about health online, put people in touch with others in similar positions, offer services such as computerised cognitive behavioural therapy and keep people in touch with healthcare professionals – for example, texting reminders of appointments. Use of technology can support innovation, increase choice and make services more accessible – for example, for deaf people – while being more cost effective. Technology can also offer a less stigmatising way of accessing support.

4.34 Improved use of information technology can also promote better and more systematic collection, analysis and use of information across all protected characteristic groups so as to improve delivery and measure outcomes.

Good practice example

The 5 Boroughs Partnership NHS Foundation Trust, covering the boroughs of Halton, Knowsley, St Helens, Warrington and Wigan, has introduced a 'Big Brother' booth where service users can give their views directly to staff and Trust board members in a way that is much more direct and compelling than using traditional feedback methods. Two simple requests are made: 'Tell us something you think we do well', and 'Tell us something you think we can improve'. The film footage is used to inform the Trust board, service users, carers and partner organisations. It is also used in staff training.

5: IMPROVING OUTCOMES IN MENTAL HEALTH: THE GOVERNMENT'S ROLE

5.1 This chapter sets out what government will do, at national and local levels, to keep people well, and to improve outcomes for people who develop mental health problems. It covers joint decision-making mechanisms at national and local levels, actions across government to improve outcomes and the reforms of the health and social care systems.

Joint decision-making mechanisms

5.2 The Coalition Government is committed to ensuring that mental health has a high priority across all government departments and that action across government is co-ordinated to best support local initiatives. The Government will only succeed in meeting the ambitions it has agreed if there are mechanisms to bring together all the relevant policies from across national and local government:

- at national level, the Cabinet sub-Committee on Public Health will oversee the implementation of the strategy, and the Cabinet Committee on Social Justice will tackle many of the underlying issues; a national Inclusion Health Board is being established whose key role is to champion the needs of the most vulnerable. It will provide expertise to prioritise action to address health inequalities among the most disadvantaged; and
- at local level, the new statutory health and wellbeing boards will bring key partners together to carry out a joint strategic needs assessment (JSNA) of local needs, to ensure that the local health and wellbeing strategy responds to the identified needs, and to influence both public health and GP consortia commissioning.

Actions across government

5.3 Mental health is a priority across government. The ambitions are shared by government departments from the Ministry of Defence to the Department for the Environment, Food and Rural Affairs and the Department for Education. Indeed, most government departments have plans of action that will improve mental health outcomes. The Cabinet sub-Committee on Public Health is where these plans are brought together, and where the Government will oversee progress on this strategy. The Cabinet Committee on Social Justice will also help to ensure that there is effective cross-government action to address many of the social causes of mental health problems.

5.4 In addition to stigma and discrimination, the critical priority areas will include:

- the early years, children, young people and families;
- Improving Access To Psychological Therapies (IAPT);
- reduction in drug misuse;
- employment;
- homelessness;
- the mental health of veterans;
- the mental health of offenders; and
- co-ordinating, promoting and supporting research.

The early years, children, young people and families

5.5 The Government has pledged to increase the health visitor workforce by 4,200 to offer all families support when they become parents and are caring for young children. Health visitors will lead and deliver the Healthy Child Programme, linking with maternity services, general practices and Sure Start children's centres, and the evidence-based Family Nurse Partnership programme, thereby helping to give all children the best start in life. Pregnancy is often the time when pre-existing and developing mental health conditions surface. Some parents will require additional support to manage anxiety and depression during pregnancy and the child's early years, which can have an adverse effect on their child's development.

5.6 The Department of Health will review the models of service and practice for both health visiting and school nursing, to ensure that these staff are properly equipped to identify and help parents, infants, children and young people who need support with their emotional or mental health. The department will also work with key partners, including Health Education England, provider-based education networks and the Royal College of Nursing, to examine the skills and competencies required of CAMHS nurses.

5.7 The new Health Premium will ensure that national government funding is designed to encourage local authorities to promote equality and narrow the gaps in health between those living in deprived areas and those in affluent areas. This will be done as part of government's broader approach to Payment by Results, for example, through the Early Intervention Grant. From April 2011 schools will have further funding to support children from low-income families via the Pupil Premium.

5.8 The Department of Health has created a focus on how the NHS reforms can contribute to improved outcomes for children and young people through an engagement document, *Achieving Equity and Excellence for Children*,[70] to address key issues identified with children's health services, including those arising from Professor Sir Ian Kennedy's report[71] on children's health services.

5.9 The Department for Education has introduced an **Early Intervention Grant**, which will provide a substantial new funding stream for early intervention and preventative services for children, young people and families. It is not ring-fenced, enabling significantly greater freedom at local level, to respond to local needs and drive reform, while supporting a focus on early intervention in the early years and up through the age range. It will bring together funding for a number of early intervention and preventative services, including Sure Start children's centres. Schools and local areas report significant benefits from the Targeted Mental Health in Schools (TaMHS) programme, and the Early Intervention Grant includes funding for targeted mental health support for children and young people.

5.10 TaMHS, which has been rolled out to school clusters in all local authorities in England, provides school-based early intervention and targeted mental health support for vulnerable children (aged from 5 to 13) and their families. This can involve one-to-one work, group work or work with parents and carers.

5.11 For adolescents, multi-systemic interventions that involve young people, parents, schools and the community have been shown to reduce conduct disorder, improve family relationships and reduce costs to the social care, youth justice, education and health systems. Families often experience multiple problems, such as substance misuse or mental health problems, parenting problems, child neglect and behaviour problems in school, or involvement in offending. Evaluation of family intervention has shown reductions in mental health problems, drug or substance misuse and domestic violence.[72] More details are given in *No Health Without Mental Health: Delivering better mental health outcomes for people of all ages*.

Supporting families with multiple problems

5.12 A national campaign to turn around the lives of families with multiple problems is under way. Around 2% of families in England (117,000) have at least five or more problems, which often include mental health problems. There are three strands to the campaign:

- Invest to test and share – a small number of exemplar areas will test out new approaches, to make a local difference and attract national interest. The first area will focus on helping adult members of families with multiple problems gain access to employment.
- Learn from success – 'mentor' areas with a track record of successfully supporting families will receive government support to become dissemination hubs to help other areas apply high-quality evidence of what works.
- Break down barriers – from April 2011 local agencies in the first 16 areas (28 local authorities) will be able to create

a Community Budget freeing up money to be spent on innovative types of family intervention services that address the needs of the whole family. More details are given in *No Health Without Mental Health: Delivering better mental health outcomes for people of all ages*.

Improving Access to Psychological Therapies

5.13 The Government is investing around £400 million over the Spending Review period to ensure that adults with depression and anxiety in all parts of England have access to a choice of psychological therapies. This investment will also enable the expansion of psychological therapies in children and young people's services. The Government will also explore:

- how older adults and their carers can better be supported by psychological therapies; and
- the application of psychological therapies to people with severe and enduring mental illness, people with physical long-term conditions and those with medically unexplained symptoms.

5.14 At local level, employment support providers and psychological therapy services will work together to improve the way that working-age people with mental health problems receive help to work or to get back to work when problems arise. A supporting document, *Talking Therapies:* * *A four-year plan of action*, has been published alongside this strategy.

Reduction in drug misuse

5.15 A new drug strategy to tackle drug dependence and promote a recovery-led approach to help people rebuild their lives was published in December 2010.[73] A clear association exists between mental illness and drug and alcohol dependence. People experiencing mental ill health have a higher risk of substance misuse. Like mental health problems, behavioural problems, including substance misuse, frequently start early in life. For young people, emotional and behavioural disorders are associated with an increased risk of experimentation with, misuse of and dependence on drugs and alcohol.[74] The approach adopted by this strategy, of promoting mental wellbeing, preventing mental illness and early intervention as soon as the problem arises, will also help to reduce the risk of substance misuse across the population. Dual diagnosis (co-existing mental health and drug and alcohol problems) covers a wide range of problems. It is important that the appropriate services are available locally in the right settings including the provision of fully integrated care, when this is appropriate, to meet this breadth of need. The Government will continue to actively promote and support improvements in commissioning and service provision for this group, their families and carers.

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* Talking therapies is a common term used to describe a wide range of psychological therapies. It is also the title of the four-year plan of action. In this document we use psychological therapies to describe the broad range which sometimes includes play and non-verbal activities.

Alcohol Misuse

5.16 Alcohol misuse is one of our main public health challenges, with 1.6 million people dependent on alcohol in 2007. As one of a number of documents setting out our new public health approach in more detail, we will publish an alcohol strategy document in summer 2011. The Public Health Outcomes Framework, under consultation to March 2011, includes a proposed indicator on alcohol-related hospital admissions. In our new strategy, we will set out how we propose to tackle the burden of illness, injury, and death from alcohol misuse.

Employment

5.17 The Government is working to help people with mental health problems to enter, stay in and return to employment. It is also supporting employers to promote the wellbeing, resilience and mental health of their staff.

5.18 We know that early intervention can improve employment outcomes, including helping people to stay in work. High-quality employment support will be geared towards meeting individuals' employment needs. Some individuals will be able to obtain or retain employment with 'light touch' support. A fundamental principle is that individuals should be enabled to take action themselves, where they can. This support may be provided by organisations such as Jobcentre Plus or other employment providers. The quality of their support will be helped by effective relationships with health services. Other people will need long-term rehabilitation to progress to employment. Progress is the key, and should be a benchmark of provision. High-quality employment support will also be based on an appropriate understanding of psychology and work, including the importance of:

- confidence in returning to and retaining work;[75]
- employers' and individuals' beliefs that the individual can perform the job and that their condition is manageable in the workplace;
- the interaction between appropriate work and wellbeing; and
- employers making appropriate recruitment decisions and managing workplace health.

5.19 The Department for Work and Pensions is reforming the Welfare to Work programme, ensuring that work always pays, by replacing existing means-tested working-age benefits with a single Universal Credit. Existing support will be consolidated into a new integrated Work Programme to provide help for people to move into work. It will operate a differential funding model which will provide additional support for people who have traditionally been harder to help – including mandatory Employment and Support Allowance customers, and customers who were recently in receipt of Incapacity Benefit.

5.20 Programmes to help people include Work Choice, which will help disabled people with complex barriers to employment find and stay in work (including self-employment); and Access to Work, which provides financial support for individuals and employers to make adjustments, so that people with health conditions can remain in work. Reforms launched in December 2010 have allowed people to receive an indicative decision on their eligibility for the scheme before applying for a job. The Government has also asked Liz Sayce, chief executive of the Royal Association for Disability Rights (RADAR), to conduct an independent review of specialist disability employment programmes. The review, due to report in summer 2011, will evaluate current specialist disability employment programmes and make recommendations.

5.21 Cross-government action is also helping people to stay in work. The Government's innovative Fit for Work Service pilots are multi-disciplinary projects delivered by local providers, focusing on early intervention and designed to get workers on sickness absence back to work faster and to keep them in work. The programme is being evaluated and the results, due in late 2011, will enable us to determine what works and in what circumstances.

5.22 The new 'fit note' was introduced in April 2010, allowing GPs and individuals to focus on how to get people on sick leave back into work. Central government will support the NHS to embed this and implement the fit note electronically in GP surgeries as soon as possible. The Government is also examining the incentives in the sickness absence system, with a view to reducing the number of people who fall out of work because of health conditions and who end up on benefits.

5.23 Included in the IAPT commitment is the provision of funding to ensure that every area has an employment co-ordinator who will work in conjunction with local Jobcentre Plus offices, employers and occupational health schemes. This money will also go towards funding provision of employment advice in IAPT services. The children and young people's IAPT programme will learn from these initiatives and consider the applicability of these principles to supporting children and young people with mental health problems in education.

5.24 The Government will also shortly be consulting with business on extending to all employees the right to request flexible working, which will help carers of people with mental health problems to manage their caring role alongside work.

Homelessness

5.25 People who are homeless have 40–50 times higher rates of mental health problems than the general population. They are also 40 times less likely to be registered with a GP. It is therefore essential that we improve access to and take-up of mental health services among homeless people, and ensure that such services are designed with the particular needs of these groups in mind and that such services take account of the very diverse range of mental health needs and dual diagnosis, and include an outreach element.

5.26 The JSNA and the new health and wellbeing boards are key to ensuring that commissioning of primary care health services responds to the needs of local people, with a new requirement to tackle health inequalities. This will ensure that health services are designed to address the health needs of groups often previously excluded from primary healthcare services. The JSNA will bring together assessments of need, including on wider outcomes such as housing, to promote joint commissioning.

5.27 If mental health and accommodation services are not properly integrated, people can be discharged from acute mental health wards when they have no place to live. This harms people's recovery, leading to further treatment and potential re-admission.

5.28 Homeless people need good-quality housing to facilitate recovery and independent living. The Government is continuing its investment in the Places of Change programme to help improve the quality of hostel accommodation, and to help providers to deliver more appropriate services to rough sleepers and to help them to make the transition into a settled home, training or employment.

5.29 In addition, the Government has established a Ministerial Working Group on Preventing and Tackling Homelessness to deal with the complex causes of homelessness. Improving access to mental health services is critical to the Government's objective of ending street homelessness. Homelessness outreach teams often need the involvement of mental health teams to take entrenched rough sleepers off the streets. Mental health services need to be delivered in close co-ordination with drug and alcohol services if they are to offer effective support for adults with complex, multiple needs, building on established good practice, such as the New Directions Team in Merton.

The mental health of veterans

5.30 The Military Covenant provides the basis for government policy aimed at improving the support available to the armed forces community. Mental health services have a key role to play in fulfilling this covenant.

5.31 Ways to provide additional help are being explored through six joint Ministry of Defence/NHS mental health pilots. The findings will assist other mental health services to make special provision for veterans during 2011/12.

5.32 As set out in September 2010, the Department of Health has committed to provide funding to ensure the best treatment possible for veterans with mental health problems by:

- creating further veterans therapist posts in NHS trusts;
- exploring the use of online counselling services;
- extending the Combat Stress helpline to function 24 hours a day, seven days a week;
- providing training to GPs and other NHS staff who may come into contact with veterans with mental health needs; and
- raising awareness among veterans themselves about services available to those with mental health problems.

5.33 The Department of Health has provided grant funding to Combat Stress to enable it to work directly with mental health trusts to ensure that the services it provides are accessible to and appropriate for military veterans. There is more information on this work in *No Health Without Mental Health: Delivering better mental health outcomes for people of all ages*.

5.34 In addition, a number of sites involved in the talking therapies programme are tailoring their services to the needs of veterans.

The mental health of offenders

5.35 Recommendations from Lord Bradley's report on improving mental health and learning disability outcomes for offenders[76] have been acted upon with the aim of ensuring that offenders have the same access to mental health services as the rest of the population and that mental health issues are picked up as early as possible in their interaction with the criminal justice system. Lord Bradley's report also proposed rolling out a national liaison and diversion service, which was agreed by Government for implementation by 2014.

5.36 The Ministry of Justice Green Paper[77] has supported this approach. The Department of Health, the Ministry of Justice and the Home Office are working with the NHS, which has funding and commissioning responsibility for diversion services. Together, they will identify a number of diversion pathfinders from existing services that will help to shape best practice, quantify the benefits and develop appropriate quality standards. In addition, further work will support development of mainstream service capacity to treat those referred by diversion services. We will aim to evaluate the pathfinder work by 2012 and, subject to positive results, roll out a national implementation programme. This work will include diversion services for young people.

5.37 Mental health secure services provide treatment for people whose mental health disorders mean that they are at significant risk of harming themselves or others. Many of these patients will be detained under the Mental Health Act 1983. Many, but not all, will be convicted offenders.

5.38 As discussed in the Ministry of Justice Green Paper, we intend to reshape services for offenders with personality disorder. The implementation plan for these changes will be the subject of a separate consultation to be published shortly. The main objective of the Offender Personality Plan is to increase capacity, thereby enabling more of the most high-risk prisoners to be appropriately managed and reduce the risk of them committing further serious or violent offences.

Co-ordinating, promoting and supporting research

5.39 High-quality research is vital to improving our understanding of the causes of mental ill health and the treatment and care of those with mental health problems. Research, including mental health research, in the UK is supported by a wide range of organisations from the private, charity and public sectors.

5.40 The Department of Health, through the National Institute for Health Research (NIHR) and the Policy Research Programme, has invested significantly in mental health research and will continue to support high-quality mental health research. The NIHR will also continue to work with research councils and other funders to co-ordinate research efforts, consistent with the recently published MRC *Review of Mental Health Research*.[78]

Reforms to the health and social care systems

5.41 A new architecture and approach for the NHS, public health and adult social care was set out in the NHS White Paper *Equity and Excellence: Liberating the NHS*, the public health White Paper *Healthy Lives, Healthy People* and in *A Vision for Adult Social Care: Capable communities and active citizens*.

5.42 Some of the key components of the new architecture are:

- an outcomes approach (rather than top-down process targets);
- local leadership via health and wellbeing boards; and the role of local authorities in commissioning for public health, including public mental health;
- a new integrated public health service – including Public Health England;
- an independent NHS Commissioning Board;
- GP commissioning consortia;
- HealthWatch England – an independent consumer champion within the Care Quality Commission (CQC);
- local HealthWatch to represent the views of patients, carers and the public

to commissioners and provide local intelligence for HealthWatch England; and

- a range of ways of improving quality of services and meeting the aspirations of service users – including NICE Quality Standards, the CQC, Payment by Results, Quality Accounts and a more competitive market for providers.

An outcomes approach

5.43 Three outcomes frameworks have been developed: for the NHS, public health and adult social care. Together they will provide a coherent and comprehensive approach to tracking national progress against an agreed range of critical outcomes. The NHS Outcomes Framework will be refined on an annual basis to make sure that the outcomes that matter to patients are included and that the indicators being used best capture those outcomes. The Public Health and Adult Social Care Outcomes Frameworks are currently subject to consultation. This strategy will inform the development of outcome indicators over the lifetime of these frameworks. The mental health objectives are critical to the delivery of all of the three outcomes frameworks.

5.44 The development of meaningful, high-level outcomes for children and young people is still at an early stage. The Department of Health is very aware of the need to develop a considered way forward – working with its partners in the Department for Education and elsewhere – building on the learning from, for example, the proposed Adult Social Care Outcomes Framework.

5.45 It will be a priority to agree key outcome measures with service users, including children, young people and their families, and with the sector as a whole.

5.46 The outcomes frameworks are not, as a whole, disease-specific. They apply equally to mental and physical health, and will be understood as such by the NHS Commissioning Board, Public Health England and local government. For example, Domain 2 in the NHS Outcomes Framework: 'Enhancing quality of life for people with long-term conditions' focuses on generic outcomes that matter most to people with any long-term condition. We know not only that some mental health problems are long term but also that the rates of mental health problems in people with long term physical illness are high. To improve quality of life for this group of people means that their mental health needs should be identified and met. This domain contains two improvement areas of specific relevance to mental health:

- enhancing the quality of life for people with mental illness – employment of people with mental illness; and
- Enhancing the quality of life for carers – health-related quality of life for carers (EQ-5D).*

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* EQ-5D is a trademark of the EuroQol Group. Further details can be found at www.euroqol.org

5.47 In the proposed Public Health Outcomes Framework, all the five proposed domains include elements relevant to mental health and wellbeing and will contribute to the delivery of mental health priorities. For example, in Domain 2: 'Tackling the wider determinants of ill health', **all** the proposed indicators measure determinants of mental ill health. In turn, reducing mental ill health will contribute to the improvement of overall health and wellbeing.

5.48 *Transparency in Outcomes: A framework for adult social care* sets out a strategic approach to quality and outcomes in adult social care. It includes a number of outcomes with direct relevance to mental health, grouped within four areas:

- promoting personalisation and enhancing quality of life for people with care and support needs;
- preventing deterioration, delaying dependency and supporting recovery;
- ensuring a positive experience of care and support; and
- protecting from avoidable harm and caring in a safe environment.

5.49 All of the frameworks will develop over time. Moreover, the NHS Commissioning Board will need to look at more detailed indicators in order to develop guidance for local commissioners. Local commissioners may also need specific indicators for local priorities. Such development work is particularly necessary in both adult mental health services and CAMHS. For example, the Government needs appropriate outcome measures for recovery, and the NHS Outcomes Framework already commits the Department of Health to develop an indicator for improving children and young people's experiences of healthcare.

5.50 At the moment few standardised outcome indicators in mental health are routinely collected. However, a large number of potential measures are available. The Outcomes Compendium,[79] published in 2009, gives details of the many measures already in use which support the local development of best practice. The NHS information architecture is being developed to support better routine outcome measurement across all mental health services. The use of the HoNOS is becoming widespread. This is a widely accepted outcome measure for severe mental illness collected through the Mental Health Minimum Dataset and is being used in the roll-out of Payment by Results in mental health.

Local leadership

5.51 Local government will play a central role in ensuring that local partnership arrangements can deliver the shared mental health objectives. Partners will include social care, education, the police and criminal justice system, housing, the environment, employers, charities and voluntary organisations, as well as health.

5.52 *Healthy Lives, Healthy People*, the public health White Paper, gives a new, enhanced role to local government and local partnerships in delivering a new approach to public health and recognises that mental health is intrinsic to health and wellbeing.

5.53 The creation of local health and wellbeing boards will ensure that local partnerships work effectively together. These boards will be expected to tackle the wider economic, social and environmental determinants and consequences of mental health problems. This strategy sets out why the Government believes that local areas, through their health and wellbeing boards, will want to treat mental health as a priority.

5.54 The boards will be required to bring together elected members of local authorities, GP consortia, directors of public health, adult social services, children's services and local HealthWatch representatives. In order to engage more effectively with local people and neighbourhoods, boards may also choose to invite participation from local representatives of the voluntary sector and other relevant public services. Boards will also want to ensure input from professionals and community organisations to advise on and give voice to the needs of vulnerable and less-heard groups. This is of particular importance to mental health.

5.55 The core purpose of the new health and wellbeing boards is to develop a high-level, public, joint health and wellbeing strategy covering the NHS, public health and social care. Subject to Parliamentary approval, commissioners will be under a legal obligation to have regard to the joint health and wellbeing strategy. They will also provide a statutory forum for co-ordinated commissioning to secure better health and wellbeing outcomes, better quality care for patients and care users, and better value for the taxpayer.

5.56 At the heart of this role is the development of the JSNA. This provides an objective analysis of the current and future needs of local adults and children, and brings together a wide range of quantitative and qualitative data, including user views. The JSNA will include assessment of mental health needs across the life course. Subject to Parliamentary approval, there will be a new legal obligation on GP consortia and local authority commissioners to have regard to the JSNA in carrying out their commissioning functions.

5.57 The Government is working closely with the Local Government Group to support health and wellbeing boards to lead a new generation of JSNAs. This includes a national best practice guide to strengthen the 'JSNA challenge', for example, around disadvantaged or excluded groups, such as those with mental health needs, as well as across rural and inner city areas.

5.58 Joint NHS and social care commissioning of mental health services is likely to be the best way to develop and improve the full range of prevention, early intervention and treatment approaches.

5.59 The health and wellbeing boards will provide a key mechanism for using joint commissioning and pooled budgets. The boards could also agree funding allocation and strategies for place-based budgets to address cross-cutting health issues. Pooled budgets and other flexibilities for joint working are particularly important for mental health. GP consortia and local authorities, through their local health and wellbeing board, will have to consider how to make best use of these flexibilities. The NHS Commissioning Board will also have a duty to promote their use.

5.60 These arrangements will promote further integration of health with adult social care, children's services (including education) and wider services, including disability services, housing, employment support and the criminal justice system. This has the potential to meet people's needs more effectively and promote the best use of public resources.

A new public health service

5.61 Half of all lifetime mental health problems are already present in adolescence. Early years experiences lay the basis for mental wellbeing in later life. Reducing mental ill health and increasing mental wellbeing requires a public health approach that prioritises early years.

5.62 *Healthy Lives, Healthy People* aims to intensify the focus on early intervention and prevention of physical and mental illnesses. It recognises the importance of strengthening self-esteem, confidence and personal responsibility throughout our lives. It is built around five priorities across the life course that are vital for good mental health: starting well, developing well, living well, working well and ageing well.

5.63 *Healthy Lives, Healthy People* places a new focus on pregnancy, the first years of life and childhood through to adolescence, when the foundations are laid for lifetime good health and wellbeing. The proposed health and wellbeing boards and the JSNA will be able to provide high-quality public health input into commissioning health visiting services and will be able to strengthen links with, for example, early years services, including Sure Start children's centres, maternity services and primary care.

5.64 *Healthy Lives, Healthy People* commits to ring-fencing public health funding. Local authorities will take statutory responsibility for improving the health and wellbeing of their populations, funded by a new ring-fenced public health grant made available to upper-tier and unitary local authorities. The consultation document *Healthy Lives, Healthy People: Consultation on the funding and commissioning routes for public health* proposed that public mental health activity should be funded from the new public health budget and commissioned by local authorities in their new public health role.

NHS Commissioning Board

5.65 *Equity and Excellence: Liberating the NHS* sets out the Government's long-term vision for the NHS. The Government will create an autonomous NHS Commissioning Board, accountable to the Secretary of State, but free from political interference. It will take responsibility for securing world-class health outcomes.

5.66 The NHS Commissioning Board will come into being in shadow form by April 2011 and, subject to Parliamentary approval, will go live in April 2012. It will provide leadership for quality improvement through commissioning guidance and hold GP consortia to account for their performance and quality. It will allocate and account for resources. The Board will also promote involvement in research and the use of research evidence. Commissioning guidelines will be developed, based on clinically approved Quality Standards developed by NICE, to promote joint working across health, public health and social care.

5.67 The Secretary of State for Health will set a formal mandate for the NHS Commissioning Board. This will be subject to consultation and Parliamentary scrutiny, including scrutiny by the Health Select Committee. This mandate will include specific measures of improvement that will be compared against a small number of indicators set out in the NHS Outcomes Framework. As explained above, the framework not only includes some key mental health indicators; action will also have to be taken to improve mental health outcomes in order to achieve improvement in the high-level outcome domains.

GP consortia

5.68 Poor-quality mental health services are often associated with poor commissioning. GP consortia will replace primary care trusts in commissioning most mental health services. A small number of specialist, high-cost, low-volume services, such as secure mental health services, will be commissioned directly by the new NHS Commissioning Board.

5.69 GP consortia are well placed to understand the broad range of mental health problems experienced by people in the local population and to commission high-quality services across primary and secondary services. The consortia will work closely with secondary care and other healthcare professionals, and with community partners to design joined-up services – and optimal care pathways, taking into account NICE Quality Standards – that make sense to patients, families and the public. GP consortia will have flexibility to seek commissioning support and enter into joint commissioning arrangements, including with local authorities and charities, particularly for services that cross boundaries, such as mental health.

5.70 GP consortia will have to take account of the local JSNA and the local health and wellbeing strategy. They will be able to influence decisions about local health improvement, addressing health inequalities and promoting equality, and social care. They will be free from top-down managerial control, and supported and held to account by the NHS Commissioning Board for the outcomes they achieve.

5.71 A GP consortia pathfinder programme will test the different elements involved in GP-led commissioning, exploring some of the issues that will ensure effective implementation across the country. A number of pathfinders are focusing specifically on the commissioning of mental health services, including CAMHS.

5.72 The NHS Commissioning Board will have responsibility for authorising a GP consortium, if it is satisfied that the consortium will be able to discharge its statutory functions. It is intended that such authorisation is seen as the culmination of a prior process of development support. The shadow NHS Commissioning Board, working with strategic health authorities and primary care trusts, will ensure that consortia have the support to prepare for their statutory establishment.

5.73 The Government is working with the Royal College of General Practitioners, the Royal College of Psychiatrists, the Association of Directors of Adult Social Services and the NHS Confederation to develop guidance and support for GP consortia in commissioning effective mental health services. In addition, there will be opportunities for the voluntary and community sector and for-profit organisations to provide specialist commissioning advice on mental health to GP consortia.

5.74 The Quality and Outcomes Framework (QOF) is the main way in which GPs are held to account for high-quality care. *Healthy Lives, Healthy People* proposed that a greater proportion of the QOF will be devoted to the provision of evidence-based primary prevention indicators and secondary prevention advice and support. It is proposed that by 2013 15% of the QOF will be devoted to prevention. Health checks for people with severe mental health problems are particularly important, given the poor physical health and high health risk behaviours of this group.

HealthWatch England and role of the Care Quality Commission

5.75 The CQC will continue its role as a quality inspectorate for privately and publicly funded health and social care. With Monitor (the independent regulator of NHS foundation trusts), it will operate a joint licensing regime and the CQC will have powers to carry out inspections of mental health services. The CQC will also continue its special role under the Mental Health Act – protecting the rights and interests of patients by monitoring the way that the Mental Health Act is used and by managing the second opinion appointed doctor service. Within the health reforms, Monitor's functions will extend from being the current regulator of foundation trusts to become the economic regulator for health and social care. Monitor's general duties are consistent with this strategy, in that it will be required to protect and promote the interests of people who use health, including mental health, services.

5.76 A new consumer champion, HealthWatch England, will be created within the CQC. It will help to ensure that the voices of people with mental health problems, including children, young people and their families – who can often be marginalised – are central to the assessment of quality in specialist mental health services and in health services more generally. Health and wellbeing boards will provide leadership and support to local HealthWatch who will be able to provide advocacy services on their behalf, if requested by the local authority. HealthWatch will advise the Health and Social Care Information Centre on which information will be of most use to patients to help them to make choices about care. It will provide advice to the Secretary of State and the NHS Commissioning Board and will have powers to propose investigations by the CQC of poor services.

Local HealthWatch

5.77 Local HealthWatch will be commissioned by local authorities to provide an independent voice for patients, service users and carers of all ages throughout the commissioning cycle. It will be able to provide advocacy services on behalf of service users, including those seldom heard, such as offenders, gypsies and travellers.

Improving quality: NICE Quality Standards

5.78 A suite of NICE Quality Standards will support the delivery of outcomes, including those relevant to mental health.

5.79 Quality Standards provide an authoritative definition of what high-quality care looks like for a particular care pathway or service. They act as a bridge between the outcomes that the NHS and public health and adult social care services will be aiming to deliver and the processes and structures that are needed to make delivery possible. They are developed by NICE, working in partnership with patients, clinicians, social care professionals, commissioners, leading experts and healthcare specialists in the relevant area, drawing on the best available evidence and practice. Subject to Parliamentary approval, NICE will also have responsibility for providing Quality Standards and other guidance in the field of social care.

5.80 The Department of Health currently commissions NICE to produce these standards. Subject to the successful passage of the Health Bill, this commissioning function for Quality Standards will transfer to the NHS Commissioning Board once it is established (and, for social care and any public health

Quality Standards, will remain with the Secretary of State for Health). The Secretary of State for Health and the NHS Commissioning Board will be under a duty to have regard to Quality Standards in carrying out their functions, particularly their new statutory duty to improve service quality. The Board will also use Quality Standards in developing the commissioning guidance that GP consortia will have to have regard to.

5.81 Within the next five years, NICE will produce a broad library of standards that cover the majority of NHS activity to support the NHS in delivering the outcomes in the NHS Outcomes Framework. Quality Standards have already been produced for dementia services and are being developed for a number of services relating to mental health problems in adults, including problems such as depression, schizophrenia and bipolar disorder, and to cover the patient experience, as well as for services relating to bipolar disorder in children and young people. Given the interdependencies between mental health outcomes and the NHS Outcomes Framework, it is envisaged that NICE will be commissioned to develop Quality Standards for services relating to other mental health conditions as part of the broad library. It is likely that some of the Quality Standards for other care pathways or services will contain mental health elements.

5.82 Often, with children and young people, there is no single or clear diagnosis. In such circumstances, providers can supplement existing NICE guidance (for example, on attention deficit hyperactivity disorder or depression) with other evidence-based interventions for treating mental health problems in these age groups.

Improving quality: Payment by Results

5.83 The Government is developing a system of Payment by Results for adult mental health services. Initially the rates of payment or tariffs will be determined locally. However, the currencies or groups of service users for whom payments will be made will be agreed and made consistent nationally.

5.84 The principles on which Payment by Results will work have been developed to facilitate appropriate high-quality care:

- the currencies are based on the needs of users requiring healthcare and other support, which makes the allocation of resources more efficient and appropriate, with better quality and productivity;
- the currencies are not setting-dependent, so there is no incentive for providers to keep people in hospital longer than is necessary;
- payments will progressively reflect the quality of the service as demonstrated in outcome and other quality indicators. Payment by Results will provide a much stronger incentive to maintain and raise quality of care; and
- local commissioners and GP consortia will be responsible for ensuring that the

mental health needs of the whole of their local populations are met by service provision.

5.85 Payment by Results for children’s mental health services will also be introduced to improve incentives in the system. A national CAMHS dataset is in development for collecting and analysing information that is already recorded at local level. The dataset will support improvements in clinical practice and help to inform those who are planning or commissioning services locally about local priorities and needs.

Improving quality: Quality Accounts

5.86 Quality Accounts are public reports produced by NHS organisations about the quality of healthcare services they provide. The reports are a mechanism for helping providers to identify and focus on the issues that will make the biggest difference to quality of care. They can also be used to explain to commissioners, patients and the public which issues have been prioritised and how the organisation will address them.

5.87 All providers of NHS mental health and learning disability services have now published their 2009/10 Quality Accounts on the NHS Choices website. Evaluation of the accounts in acute trusts demonstrates that they have proved to be an effective tool for raising the profile of quality improvement and engaging boards. As organisations, including mental health providers, gain experience in this type of reporting, their Quality Accounts will be better able to explain to users how key services, such as in the area of mental health, are being improved.

Improving quality: a more competitive market for providers

5.88 There is already a plurality of providers of mental health services, including many from the private and voluntary sectors. The Government wants to go further to ensure that patients and service users will be able to choose ‘any willing provider’ on the basis of quality. ‘Any willing provider’ will be subject to NHS prices and quality. This is of particular relevance in the area of mental health, where the needs of individuals are very diverse and where different and innovative approaches may be necessary for ensuring that even the most excluded can be helped to get the care and support they need.

6: IMPROVING OUTCOMES IN MENTAL HEALTH: PROMOTING EQUALITY AND REDUCING INEQUALITY

6.1 Tackling health inequalities and promoting equality, as enshrined in the Equality Act 2010, is vital if the Government is to deliver health outcomes that are among the best in the world. As the Marmot Review demonstrated, the social gradient in many health outcomes for people in disadvantaged groups and areas accounts for England's poorer health outcomes in comparison with other similar countries.[80] Aspects of people's identity and experiences of inequality interact with each other. For example, people from black and minority ethnic (BME) groups are more likely to live in deprived areas and have negative experiences, both as a result of their ethnic identity and because of their socio-economic status and living environment.

6.2 Promoting equality refers to the inclusion and equitable treatment of protected groups and a need to eliminate discrimination, advance equality of opportunity and foster good relations within communities.

6.3 Effective approaches to reducing differences in access, experience and mental health outcomes are built from the best available evidence on why and how these variations occur. Marmot showed that, among other factors, poor childhood, housing and employment (and also unemployment) increase the likelihood that people will experience mental health problems and that the course of any subsequent recovery will be affected. These factors vary across different sections of society, with the result that some groups suffer multiple disadvantages.

6.4 The Equality Act 2010, informed by consultation with stakeholders from all sectors of the community and a major review of evidence on inequality, replaced the three existing public sector equality duties – pertaining to disability, race and gender – with a new Equality Duty. It covers nine **protected characteristics**, and there is a public sector duty to advance equality and reduce inequality for people with these protected characteristics, which are:

- age
- disability
- gender reassignment
- marriage and civil partnership
- pregnancy and maternity
- race
- religion or belief
- sex
- sexual orientation.

6.5 The Analysis of the Impact on Equality (AIE, formerly called an Equality Impact Assessment (EqIA)), which accompanies this strategy, considers the evidence of the differential impact of these characteristics and sets out an action plan to address these issues. There is also an extensive set of evidence of different types annexed to the AIE which underpins it. The Analysis also sets out actions for promoting equality.

6.6 There are three aspects to reducing mental health inequality:

- tackling the inequalities that lead to poor mental health;
- tackling the inequalities that result from poor mental health – such as lower employment rates, and poorer housing, education and physical health; and
- tackling the inequalities in service provision – in access, experience and outcomes.

6.7 *Healthy lives, healthy people* makes clear the Government's ambition to reduce health inequalities and improve the health of the poorest, fastest.

6.8 That has not always been the effect of previous initiatives, and there are some significant inequalities, both in the differing rates of mental health problems across different groups and in people's access to, experience of and outcomes from mental health services. Some of the evidence is summarised here. More is set out in the AIE that accompanies this strategy.

6.9 A fundamental principle in tackling inequality is that all protected characteristics should be considered so as to avoid unjustifiable discrimination. At local level, needs assessment will determine the areas of greatest inequality that local strategies will need to address.

6.10 Reducing inequalities requires a multi-stranded approach that tackles the economic, social and environmental determinants and consequences of mental health problems. Such an approach needs to take into account the fact that people have more than one protected characteristic. Approaches must also take into account people's living environments and social circumstances, which are critical to the onset and course of their mental health problems. This approach is embedded in both this strategy and other cross-government initiatives. Tackling the determinants is a key strand of *Healthy Lives, Healthy People*. It stressed the importance of both universal approaches and targeted interventions aimed at those facing the greatest disadvantage in society, so that their health can improve most quickly. *Healthy Lives, Healthy People* emphasised the need to start early, so as to ensure that all children have the best start in life and continue to develop well.

6.11 Inequalities that arise for people with protected characteristics are compounded by the stigma and discrimination surrounding mental ill health. That is why the Government has taken action to tackle public attitudes towards mental illness, one of the key objectives of this strategy. This is covered in Chapter 3 above (objective (vi)).

6.12 One of the cornerstones of tackling inequalities in service provision is delivering a truly personalised approach that identifies the specific needs of each individual and their family and carers, so that they have more control over the support they receive.

6.13 The Government is working to close the equality gap for all people with protected characteristics. It has also identified a number of other groups that are known to have reduced access to mental health services, for example homeless people, veterans, people with personality disorder and offenders.

6.14 In this chapter we consider the specific groups protected by the Equality Act 2010. Research evidence[81] has highlighted the challenges. Strategic solutions should be informed by current positive practice and other new and emerging research.

Improving outcomes for older people with mental health problems

6.15 Depression is the most common mental health problem in older people. Some 25% of older people in the community have symptoms of depression that may require intervention. Symptoms of depression are common and sometimes short-lived, but for some may develop into a clinical depression. Some 11% of older people will have minor depression and 2% a major depression.[82] Older people with physical ill health, those living in residential care and socially isolated older people are at higher risk.[83] Yet these problems often go unnoticed and untreated. Studies show that only one out of six older people with depression discuss their symptoms with their GP and less than half of these receive adequate treatment.[84] As well as the impact on quality of life, untreated depression in older people can increase need for other services, including residential care. However, older people can respond very well to psychological and medical treatments. This includes carers of people with dementia, so that they are better supported to manage challenging behaviours. As the Department of Health completes the nationwide roll-out of psychological therapy services for adults who have depression or anxiety disorders, we will pay particular attention to ensuring appropriate access for people over 65 years of age. People who remain healthy into older age are more likely to continue in employment if they wish, and to participate actively in their communities. The supporting document, *Talking Therapies: A four-year plan of action*, explains this in detail. We will continue to monitor older people's access to the new psychological therapy services.

6.16 Improving the quality of care for people with dementia and their carers is a major priority for the Government. For every 10,000 people over the age of 65, 500 have dementia, with 333 not having this diagnosed. The Government is committed to more rapid improvement in dementia care, through local delivery of quality outcomes and local accountability for achieving them. This approach is set out in *Quality Outcomes for People with Dementia: Building on the work of the National Dementia Strategy*[85] (September 2010) – the revised, outcomes-focused implementation plan for the National Dementia Strategy. More information on the mental health of older people is provided in the companion document to this strategy, *No Health Without Mental Health: Delivering better mental health outcomes for people of all ages*.

6.17 The Department of Health, the Royal College of General Practitioners, the Royal College of Nursing, the Royal College of Psychiatrists and the British Psychological Society will continue to co-operate and develop ways of improving the recognition of depression in older people in primary care. A new training programme will be made available shortly.

6.18 From 2012 the NHS and local government will be required to comply with the Equality Act 2010 and its provisions on discrimination on grounds of age.

Improving outcomes for black and minority ethnic people with mental health problems

6.19 The evidence on the incidence of mental health problems in BME groups is complex. The term BME covers many different groups with very different cultural backgrounds, socio-economic status and experiences in wider society. People from BME groups often have different presentations of problems and different relationships with health services. Some black groups have admission rates around three times higher than average, with some research indicating that this is an illustration of need. The rates of mental health problems in particular migrant groups, and subsequent generations, are also sometimes higher. For example, migrant groups and their children are at two to eight times greater risk of psychosis. More recent arrivals, such as some asylum seekers and refugees, may also require mental health support following their experiences in their home countries.

6.20 African-Caribbean people are particularly likely to be subject to compulsory treatment under the Mental Health Act. South East Asian women are less likely to receive timely, appropriate mental health services, even for severe mental health conditions.

6.21 Tackling the inequalities for BME communities has been a central focus for a number of years. However, the outcomes have in some ways been disappointing.

6.22 *Race Equality Action Plan: A five-year review*[86] looks back at the work of the Delivering Race Equality in Mental Health Care programme and describes some of the key challenges, successes and learning. It provides a strong base from which commissioners and service providers can make improvements. These will rely on:

- local collection and monitoring of information on ethnicity and culture;
- better use of these data to inform commissioning and provision in health and social care;
- a focus on outcomes that work for individuals and communities;
- monitoring and evaluating effectiveness of service delivery, especially around equality needs; and
- establishing mechanisms that allow local user groups to engage with providers and commissioners, and that empower and support them so that they can engage effectively.

6.23 This will be underpinned by the new statutory responsibilities of the NHS Commissioning Board and GP consortia. In addition, Department of Health research and analytical staff will continue to make best use of research in developing effective approaches for reducing race inequality in mental health.

Improving outcomes for disabled people with mental health problems

6.24 There are two aspects to the consideration of the outcomes for disabled people with mental health problems:

- people with mental health problems meet the criteria within legislation for disabled people; and
- disabled people with mental health problems may face barriers, either barriers to physical access or communication barriers (particularly in the case of deaf people). This is critical in mental health provision, which relies heavily on communication and relationships for supporting improved outcomes. Also, an estimated 25–40% of people with learning disabilities have mental health problems.

6.25 Commissioners and service providers will need to continue to ensure that mental health services are accessible to all disabled people. Arrangements need to be in place for deaf people so that they are able to communicate, and have equitable experiences of and outcomes from services.

6.26 The special educational needs and disability Green Paper will consider, among other things, how to make sure that there is better early intervention to prevent later problems for children with special educational needs and disabilities, including those who have underlying or associated mental health problem.

6.27 There are two important aspects to the improvement of mental health services for people with learning disabilities and autism:

- inclusivity of mainstream mental health services for people with learning disabilities who have mental health problems; and

- development of appropriate skills and provision of adjustments to meet the individual needs of people with learning disabilities and autism (recognising the increased risks of a range of physical and mental health problems for this group).

6.28 People with autism may be refused support because they do not fit easily into mental health or learning disability services. This has been a long-standing problem. The autism strategy, *Fulfilling and Rewarding Lives*, and the recent statutory guidance *Implementing 'Fulfilling and Rewarding Lives': Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy*,[87] outlined priorities for improvement, including:

- the development of diagnostic services and pathways to care and support;
- the availability of mental health services for people with autism, where appropriate; and
- greater awareness of autism among healthcare and social care professionals.

Improving outcomes for lesbian, gay and bisexual people with mental health problems

6.29 People who are lesbian, gay and bisexual all have a higher risk of mental health problems and of self-harm.[88] They also suffer more attacks and violence. Experiences of mental health services are reportedly poor, and monitoring of sexual orientation is patchy, making it less easy to develop tailored service responses. A priority action for securing improved outcomes is to achieve routine local monitoring of access to services, experience and outcome by sexual orientation.

Improving outcomes in relation to gender inequality

6.30 There are many differences in the rates and presentation of mental health problems between men and women, and boys and girls. Improved awareness of these issues among staff is important.[89]

Women

6.31 Recorded rates of depression and anxiety are between one and a half and two times higher for women than for men. Rates of deliberate self-injury are two to three times higher in women than men. Women are at greater risk of factors linked to poor mental health, such as child sexual abuse and sexual violence – an estimated 7–30% of girls (3–13% of boys) have experienced childhood sexual abuse. Around one in ten women have experienced some form of sexual victimisation, including rape. Studies have shown that around half of the women in psychiatric wards have experienced sexual abuse.

6.32 Sexual safety in inpatient and residential environments is particularly important. This includes the provision of women-only day areas in mental health service buildings and adherence to NHS policy on mixed-sex accommodation. Staff need to be supported so that they can appropriately explore with women whether they have had experience of sexual violence. Issues relating to pregnancy and maternal health are dealt with in Chapter 5 and in the AIE.

Men

6.33 Three-quarters of people who commit suicide are men. Men are three times more likely than women to be dependent on alcohol and more than twice as many men in psychiatric units are compulsorily detained.[90] Services should be sensitive to the ways in which men present mental health problems.[91]

Improving outcomes in relation to gender reassignment

6.34 This strategy uses the definitions set out in the Equality Act 2010. Gender reassignment refers to, among others:

- people who plan to, or have undergone, physiological change or other attributes of sex; and
- people who are referred to as transsexual.

6.35 People who identify with this protected characteristic are subject to some of the greatest discrimination in our society. They are at increased risk of alcohol and substance misuse, suicide and self-harm.[92] It is important that staff in health, social and education services are aware of the raised risks in these groups. The issue of increased suicide risk will be covered in more detail in the forthcoming suicide prevention strategy.

Religion or belief

6.36 Inequalities arise in mental health services, in relation to religion or belief, in four main ways:

- The relationship with other aspects of identity (for some cultures ethnicity and religion are virtually inseparable). Service data show that more people from BME backgrounds identify themselves as religious. By failing to address religion, services disproportionately affect people from BME backgrounds.
- Potential for people who hold religious or other beliefs to have poorer experiences of services because core aspects of their identity are overlooked or they have no means of religious expression (for example, prayer rooms). This may cause anxiety and prove detrimental to their recovery.
- Evidence indicates that religion may be protective, particularly in relation to suicide.
- The role of religion or belief in people’s explanations for their mental health problems – different conceptualisations and language between an individual and services will affect engagement and success of treatment and care.

6.37 If positive outcomes are to be achieved, services will need to incorporate religion and belief into the assessment of individuals. Local services will achieve better outcomes if they make resources and facilities available for people to express their religion or belief.

The role of government in reducing health inequalities

6.38 The Department of Health has made tackling health inequalities a priority. It is under a legal obligation to promote equality across the characteristics protected in the Equality Act 2010. Subject to Parliamentary approval, the NHS Commissioning Board and GP consortia will be under a specific statutory obligation to reduce inequalities in healthcare provision.

6.39 One of the underpinning principles in the development of the NHS Outcomes Framework has been the need to promote equality and reduce inequalities in health outcomes. From 2012/13, the framework will be used by the Secretary of State for Health to hold the NHS Commissioning Board to account, and to achieve levels of ambition where they have been agreed. Levels of ambition will, where possible, take into account the variation and inequalities in outcome indicators, such as equalities characteristics, disadvantage and where people live. The framework will help the NHS Commissioning Board to play its full part in promoting equality in line with the Equality Act.

6.40 The Department of Health has created an Equality and Diversity Council, chaired by the NHS Chief Executive, to raise the profile of equality and diversity issues across the NHS and to support the NHS in implementing the Equality Act. The Council reports to the NHS Management Board and is working to develop and deliver change to make the NHS more personal, fair and diverse. Goals include creating a framework that encourages NHS organisations and staff to work closely with the communities they serve, and ensuring that managers consider equality and diversity issues and champion good practice.

6.41 The Council has commissioned work to develop an Equality Delivery System for the NHS, which will draw on current good practice. This system is being designed to improve the delivery of personalised, fair and diverse services to patients, and to provide working environments where staff can thrive. So far, over 660 people from NHS organisations, patient groups and other interest groups have provided feedback on the proposals.

6.42 The question of equality in mental health raises highly complex – and often highly sensitive – issues. The Department of Health will continue to work with people affected, carers, families, communities and relevant agencies to refine its understanding of the issues. The Department will reconvene the Ministerial Advisory Group on equality in mental health, where the leading organisations in the field will be invited to work with the Minister of State for Care Services on progress.

7: IMPROVING QUALITY AND MAKING THE MOST OF OUR RESOURCES

7.1 Mental health problems cost both individuals (and their families) and the economy an enormous amount. There is a growing body of evidence that some approaches to addressing mental health issues can produce better outcomes while achieving significant reductions in costs. This is of particular relevance at a time of economic constraint. Although the NHS as a whole was protected from cuts in the Spending Review, rising demand means that the NHS has to find up to £20 billion in efficiency savings by 2014. As nearly 11% of England's annual secondary care health budget is allocated to mental health care, the mental health sector cannot be exempt from having to make savings. There are many interdependencies between physical and mental health, so any efficiencies in mental health services need to be carefully thought through so that false economies and greater costs elsewhere in the health and social care system are avoided. The Coalition Government has made it clear that it expects parity of esteem between mental and physical health services.

7.2 It is for local commissioners to ensure that when services are decommissioned or commissioned, the needs of the whole population and the best evidence of what works are taken into account.

7.3 There are four main ways of increasing value for money in mental health services:

- improving the quality and efficiency of current services;
- radically changing the way that current services are delivered so as to improve quality and reduce costs;
- shifting the focus of services towards promotion of mental health, prevention of mental illness and early identification and intervention as soon as mental illness arises; and
- broadening the approach taken to tackle the wider social determinants and consequences of mental health problems.

7.4 These are not mutually exclusive and elements of all may be considered when planning and designing local solutions. Local commissioners and providers should also consider joining together with non-clinical agencies such as employment or housing support services. Further details are contained in the supporting document, *No Health Without Mental Health: Delivering better mental health outcomes for people of all ages*.

7.5 It is important to identify when and where benefits will be realised, and over what timescale. For example, investment in different health and educational approaches when dealing with vulnerable children and families may result in reduced costs in the medium and long term for the criminal justice system and for the Department for Work and Pensions, through reduced crime and increased employment and economic productivity.

7.6 Fostering innovative practice, supporting research and ensuring good evaluation are critically important if the Government is to continuously maintain high-quality and efficient services.

Improving the quality and efficiency of current services

Quality, Innovation, Productivity and Prevention

7.7 At a time of financial and demographic pressure, improving quality while increasing productivity and effectiveness will be vital for any improvements in care. The Quality, Innovation, Productivity and Prevention (QIPP) programme within the NHS is designed to address this challenge.
A number of local NHS plans for delivering QIPP include mental health provision, reflecting both the importance of mental health services and the resources currently committed to providing them. In line with this, the Government has initiated work at both national and local levels, with the aim of delivering improvements over a two-year period from 2011/12.

7.8 There are three workstreams:

- the acute care pathway – avoiding hospital admissions through effective joined-up community care and ensuring that hospital inpatient care itself is effective and that unnecessarily long stays are avoided (for example, by action to tackle delayed discharges);
- out of area care – getting better quality and better value through ensuring that appropriate in-area care is available where this is a better solution and commissioning effectively so that care is managed well, in terms of both care pathways and unit costs; and
- physical and mental health co-morbidity – getting better diagnosis and treatment of mental health problems for those with long-term physical conditions, and getting identification and treatment of anxiety or depression for those with medically unexplained symptoms. One example is the use of a 'collaborative care' approach when treating depression in people with type 2 diabetes in primary care. It has been estimated that introducing this nationally has the potential to save the NHS and social care around £3.4 million in four years, with a further £11.7 million of benefits to individuals from improved productivity.

7.9 The recent vision for adult social care emphasised that the additional £2 billion of funding made available in the Spending Review to support the delivery of adult social care must be accompanied by re-design of services to deliver efficiencies. This could include:

- better joint working with the NHS;
- helping people to stay independent for longer, with a focus on re-ablement services, and more crisis or rapid response services;
- more streamlined assessment; and
- a general presumption that responsibility for commissioning and providing services should be separated.

7.10 In addition, as the *Use of Resources in Adult Social Care*[93] highlighted, there remain dramatic differences between councils in their proportion of spend on long-term nursing and residential care. Councils are expected to look closely at how they can reduce spend on residential care and increase community-based provision.

7.11 The Department of Health will be issuing best-practice guidance and 'cost calculators' so that commissioners will be able to estimate savings in all three QIPP workstream areas later this year.

7.12 These workstreams align closely with the objectives of this strategy. The QIPP approach will be a powerful means of delivering much of the agenda. Further details are set out in the supporting document *No Health Without Mental Health: The economic case for improving efficiency and quality in mental health*.

Radically changing the way that current services are delivered so as to improve quality and reduce costs

7.13 Two examples of more radical reforms are as follows:

- Medically unexplained symptoms have been shown to cost the NHS in England £3 billion every year. A review of a large number of studies found that cognitive behavioural therapy is very effective for those with identified mental health problems.*
- Early Intervention in Psychosis services for young people aged 14–35 with the first onset of psychosis have been shown to benefit individuals, reduce relapse, improve employment and educational outcomes, and reduce risk of suicide and homicide. A recent study has shown that providing an early intervention approach rather than standard mental health care could deliver savings of £38,000 per person over 10 years (about 20% of these costs were incurred in NHS services). Early detection services for people with even earlier symptoms of psychosis (at-risk mental state) have also been estimated to deliver savings – in this case around £23,000 per person over 10 years (about 25% of these costs were incurred in the NHS).

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* See *No Health Without Mental Health: The economic case for improving efficiency and quality in mental health.*

Shifting the focus of services towards promotion of mental health, prevention of mental illness and early identification and intervention as soon as mental illness arises

7.14 There are many examples of effective early intervention. Two examples that demonstrate a strong evidence base are as follows:

- Intervening early for children with mental health problems has been shown not only to reduce health costs but also to realise even larger savings from improved educational outcomes and reduced unemployment and crime. These approaches not only benefit the individual child during their childhood and adulthood but also improve their capacity to parent. They can therefore break cycles of inequality running through generations of families.
- Conduct disorder is the most common childhood mental disorder, for which parenting support interventions are recommended as first-line treatment.[94] A number of studies have shown that effective parenting interventions and school-based programmes can result in significant lifetime savings. Parenting interventions for parents who have children with conduct disorder cost about £1,200 per child. They have been shown to produce savings of around £8,000 for each child over a 25-year period (14% of the savings are in the NHS, 5% in the education system and 17% in the criminal justice system).

Broadening the approach taken to tackle the wider social determinants and consequences of mental health problems

7.15 One example of this approach is providing face-to-face debt advice. Evidence suggests that this can be cost-beneficial within five years. The upfront cost of debt advice is more than offset by savings to the NHS, savings in legal aid, and gains in terms of employment productivity, even before taking into account savings for creditors.

8: CONCLUSION

8.1 This strategy spells out the Coalition Government's commitment to improving mental health and mental health services. To achieve this, the Government has agreed six high-level objectives with partner organisations, which set out the joint determination to improve mental health outcomes for all. This strategy also describes a number of specific commitments to:

- improve the mental health and wellbeing of the population;
- keep people well; and
- ensure that more people with mental health problems regain a full quality of life as quickly as possible.

8.2 These outcomes will be delivered by putting more power into people's hands at local level to ensure effective planning and commissioning of services that meet locally agreed needs. Accountability is a key driver of the current reforms. The public sector, including the NHS, and public health and social care organisations, has a responsibility to the public and users of services that goes further than how services are provided. The public and service users will play an active part in decisions about how priorities are determined, how public money is spent and how discriminatory attitudes to mental health can be effectively challenged.

8.3 Local action will be supported by a sustained, cross-government approach. This will be led by the Cabinet Sub-Committee on Public Health, which will champion mental health across the whole of government. The approach will include actions that the Government can take to tackle stigma, as an employer, through its policies and partnerships, and by demonstrating leadership.

8.4 The Government will establish a Mental Health Strategy Ministerial Advisory Group which will work to realise this strategy. It will bring together the new NHS Commissioning Board and Public Health England with GP consortia, the Local Government Association, the Association of Directors of Adult Social Services, the Association of Directors of Children's Services, other government departments, the Care Quality Commission, Monitor, professional bodies, commissioners, mental health provider organisations, the voluntary and community sector, and people with mental health problems and carers.

8.5 Between 2011 and 2012, while the NHS Commissioning Board and Public Health England are being established, this group will identify actions in the transitional year for implementing this mental health strategy. The Government will review the function of this group for 2012 onwards, once the NHS Commissioning Board and Public Health England are in place. However, the Government anticipates that it will become a focus for partners to discuss how implementation of this strategy will take place and review progress. The group may advise on improved indicators for tracking progress against the mental health objectives that could be used locally, by the NHS Commissioning Board, and potentially in future iterations of outcomes frameworks.

8.6 Action at local and national levels to implement this strategy will only be effective if there is sustained partnership working across all sectors. The Ministerial Advisory Group will be the locus for achieving this.

ANNEX: A HOW WILL WE KNOW IF THINGS HAVE IMPROVED?

(See the supporting document *No Health Without Mental Health: Delivering better mental health outcomes for people of all ages* for further details under each objective.)

The Public Health Outcomes Framework

1. The Public Health Outcomes Framework consultation document proposes a number of national-level indicators to help local health and wellbeing boards and local communities track progress. While the domains will remain unchanged over the next few years, the indicators within each domain will develop over time. The indicators with particular relevance to mental health are as follows:

Vision: To improve and protect the nation's health and wellbeing and to improve the health of the poorest, fastest

Proposed indicators are:

- healthy life expectancy
- differences in life expectancy and healthy life expectancy between communities.

Domain 1: Health protection and resilience: protecting the population's health from major emergencies and remaining resilient to harm

Proposed indicators include:

- comprehensive, agreed, interagency plans for a proportionate response to public health incidents are in place and assured to an agreed standard.

Domain 2: Tackling the wider determinants of ill health: tackling factors which affect health and wellbeing

All the indicators in this domain are relevant to mental health and wellbeing. They include:

- children in poverty
- truancy rate
- school readiness: foundation stage profile attainment for children starting Key Stage 1
- first time entrants to the youth justice system
- the proportion of people with mental illness and/or disability in employment *, **
- the proportion of people with mental illness and/or disability in settled accommodation**
- employment of people with long-term conditions
- incidents of domestic abuse**
- statutory homeless households
- housing overcrowding rates
- fuel poverty
- access and utilisation of green space
- older people's perception of community safety**
- rates of violent crime, including sexual violence
- reduction in proven reoffending
- social connectedness
- the percentage of the population affected by environmental, neighbour and neighbourhood noise.

* Shared responsibility with the NHS.
** Shared responsibility with Adult Social Care.

Domain 3: Health improvement: helping people to live healthy lifestyles and make healthy choices

Proposed indicators relevant to mental health and wellbeing include:

- smoking prevalence in adults (over 18)
- incidence of low birth weight of term babies
- rate of hospital admissions as a result of self-harm
- rate of hospital admissions per 100,000 for alcohol-related harm
- number leaving drug treatment free of drug(s) of dependence
- the percentage of adults meeting the recommended guidelines on physical activity (5 x 30 minutes per week)
- hospital admissions caused by unintentional and deliberate injuries to 5–18-year-olds
- under 18 conception rate
- self-reported wellbeing.

Domain 4: Prevention of ill health: reducing the number of people living with preventable ill health

Proposed indicators relevant to mental health and wellbeing include:

- hospital admissions caused by unintentional and deliberate injuries to under 5-year-olds
- work sickness absence rate
- rate of hospital admissions as a result of self-harm
- maternal smoking prevalence (including during pregnancy)
- child development at 2–2.5 years
- smoking rate of people with serious mental illness
- emergency readmissions to hospitals within 28 days of discharge*, **
- health-related quality of life for older people.**

* Shared responsibility with the NHS.
** Shared responsibility with Adult Social Care.

Domain 5: Healthy life expectancy and preventable mortality: preventing people from dying prematurely

Proposed indicators relevant to mental health and wellbeing include:

- suicide rate
- mortality rate of people with mental illness.*

* Shared responsibility with the NHS.

2. An equivalent to 'economic participation' for children is being developed. This will fill the gap in both the NHS and Public Health Outcomes Frameworks. Attendance at school is an insufficient measure of mental health on its own; participation and achievement are also important factors.

The NHS Outcomes Framework

3. The NHS Outcomes Framework outlines a number of national-level outcome goals that can be used to measure progress. The domains will stay the same but the indicators will develop over time. For 2011/12 the indicators include the following:

Domain 1: Preventing people from dying prematurely

Improvement area

Reducing premature death in people with serious mental illness

Indicator is:

- under-75 mortality rate in people with serious mental illness.*

* Shared responsibility with Public Health England.

Domain 2: Enhancing quality of life for people with long-term conditions

Improvement areas

Enhancing quality of life for people with mental illness

Indicator is:

- employment of people with mental illness.

Enhancing quality of life for carers

Indicator is:

- health-related quality of life for carers (EQ-5D).*

* EQ-5D is a trademark of the EuroQol Group. Further details can be found at www.euroqol.org

Domain 3: Helping people to recover* from episodes of ill health or following injury

Overarching indicator

- emergency readmissions within 28 days of discharge from hospital.

* The term 'recovery' is used in both the NHS and Social Care Outcomes Frameworks. When used here it refers to clinical recovery and is not being used in the specific way in which it is used in mental health services. However, the indicators suggested are relevant to mental health outcomes.

Domain 4: Ensuring that people have a positive experience of care

Improvement area

Improving the experience of healthcare for people with mental illness

Indicator is:

- patient experience of community mental health services.

Domain 5 : Treating and caring for people in a safe environment and protecting them from avoidable harm

Overarching indicators

- patient safety incident reporting
- severity of harm
- number of similar incidents.

Applies to all NHS providers including mental health services.

4. We are committed to ensuring that outcomes for children and young people are fully reflected in the NHS Outcomes Framework as it develops over time to reflect advances in practice and data collection.

The Adult Social Care Outcomes Framework

5. *Transparency in Outcomes: A framework for adult social care*, published in parallel with *A Vision for Adult Social Care*, sets out a new strategic approach to quality and outcomes in adult social care, including new use of evidence-based Quality Standards in social care, a greater emphasis on transparency in local services, and work to reform the shared data sets which demonstrate the outcomes achieved. Proposals are subject to consultation, and include a set of outcome measures which could be used initially from April 2011.

6. The initial Outcomes Framework for adult social care sets out a number of available measures, many of which are relevant to mental health. As with the NHS and public health partners, the outcomes are grouped into four proposed domains, all directly relevant to the mental health objectives:

   - promoting personalisation and enhancing quality of life for people with care and support needs;

   - preventing deterioration, delaying dependency and supporting recovery;

- ensuring a positive experience of care and support; and
- protecting from avoidable harm and caring in a safe environment.

7. Of the specific outcome measures highlighted, many would be relevant to mental health. As well as confirming which of these have sufficient support to be used nationally, the consultation process is also expected to identify gaps in current data collections, so that further work can improve the Outcomes Framework over future iterations.

8. The framework deals directly with recovery under Domain 2, where a number of outcome measures are shared with the NHS Outcomes Framework to promote shared approaches to common areas:

Domain 2: Preventing deterioration, delaying dependency and supporting recovery

Overarching measures

- emergency readmissions within 28 days of discharge from hospital*
- admissions to residential care homes, per 1,000 population.

Outcome measures

Helping older people to recover their independence

- the proportion of older people (65 and over) who were still at home after 91 days following discharge from hospital into reablement/rehabilitation services.

Preventing deterioration and emergency admissions

- emergency bed days associated with multiple (two or more in a year) acute hospital admissions for over-75s.*

Supporting recovery in the most appropriate place

- delayed transfers of care.*

Delivering efficient services which prevent dependency

- the proportion of council spend on residential care.

* Measures drawn from NHS or other non-council data sources.

9. In addition, further outcome measures proposed in the other domains are of direct relevance to mental health objectives:

Domain 1: Promoting personalisation and enhancing quality of life for people with care and support needs

Outcome measure

Enhancing quality of life for people with mental illness

- the proportion of adults in contact with secondary mental health services in employment.

Quality measures

Promoting personalised services

- the proportion of people using social care who receive self-directed support.

Domain 3: Ensuring a positive experience of care and support

Overarching indicator

- overall satisfaction with local adult social care services.

Outcome measures

Treating carers as equal partners

- the proportion of carers who report they have been included or consulted in discussions about the person they care for.

Domain 4: Protecting from avoidable harm and caring in a safe environment

Overarching indicator

- the proportion of people using social care who feel safe and secure.

Outcome measures

Ensuring a safe environment for people with mental illness

- the proportion of adults in contact with secondary mental health services in settled accommodation.

Other potential Indicators

10. There are a number of indicators that can be used to measure progress against local strategic needs assessments. One well-evidenced example for measuring adult mental wellbeing is the Warwick-Edinburgh Mental Wellbeing Scale. Psychological therapies services already regularly measure outcomes of interventions and access to services by different groups. In addition, the implementation of Payment by Results will ensure that services use Health of the Nation Outcome Scales (HoNOS) regularly to measure outcomes in secondary adult mental health services. Other key national indicators of relevance to the mental health objectives include the following:

- The Office for National Statistics is consulting on national measures of wellbeing. Disaggregation of the data to local area detail will be useful for local planning.
- The adult and child Psychiatric Morbidity Surveys can be used to estimate the rates of mental health problems such as anxiety and depression and conduct disorder, and also to monitor changes over time.
- The 12-item General Health Questionnaire (GHQ-12) is also collected by the Health Survey of England.
- The Labour Force Survey collects the sickness absence that is attributable to mental ill health.
- The new Life Opportunities Survey may potentially provide information on a range of outcomes, including: barriers to employment, accessing health services, and participation in leisure and social activities.

Quality Standards

11. The following Quality Standards relevant to the mental health objectives are currently in development:

- Drug use disorders in over-16s
- Schizophrenia
- Bipolar disorder in adults
- Bipolar disorder in children and adolescents
- Alcohol dependence
- Depression in adults
- Postnatal care
- Drug use disorders
- Dementia
- Patient experience (generic)

- Patient experience in adult mental health care
- Safe prescribing
- Falls in a care setting
- Nutrition in hospital, including young people.

12. Further Quality Standards relevant to mental health will be considered shortly. The new approach to quality and outcomes in adult social care also describes an expanded role for NICE in preparing Quality Standards for social care, which have the capacity to increase the coverage across individual pathways. As part of its most recent selection process, the National Quality Board also identified long-term conditions/people with co-morbidities or complex needs as an important area for Quality Standard development, but additional work is required to assess the feasibility and scope of the standard before the topic can be recommended for referral to NICE.

Areas where there are fewer indicators currently available

13. There are several areas where there are insufficient indicators currently available – for example, measuring aspects of mental wellbeing – and there is also a lack of indicators covering all age groups. Some of these gaps are further detailed in the companion document *No Health Without Mental Health: Delivering better mental health outcomes for people of all ages*.

ANNEX B: SUMMARY OF COMMITMENTS OF GOVERNMENT DEPARTMENTS TO SUPPORT MENTAL HEALTH OBJECTIVES

The Cabinet Sub-Committee on Public Health will oversee the implementation of this mental health strategy. It will be supported by the Social Justice Sub-Committee, which will ensure effective cross-government action to address the social causes and consequences of mental health problems.

Mental health objective	Action	Status	Owner
Objective 1 **More people will have good mental health** *More people will have better mental wellbeing and good mental health and fewer people will develop mental health problems*	Help to prevent mental health problems by encouraging organisations to tackle the causes such as work-related stress and to promote the welfare of their staff	Under way	HSE
	Reform children's centres, focusing on the most disadvantaged (coalition commitment (CC))	New, under way	DfE
	Investigate a new approach to help families with multiple problems (CC)	New, under way	DfE
	Recruit 4,200 new health visitors (CC)	New, under way	DH
	Provide free nursery care for pre-school children (CC)	Ongoing	DfE
	Maintain priority of health and wellbeing in schools, through reviews of guidance, curriculum and Schools White Paper. Identify and disseminate evidence on supporting school transitions	New, proposed	DH/DfE
	Develop the Healthy Schools programme with businesses and charities	New	DH/DfE
	Reduce teenage conceptions through the provision of high-quality sex and relationships education and access to contraception services, and supporting teenage parents	Ongoing	DfE/DH

Mental health objective	Action	Status	Owner
Objective 1 (continued)	Create School Games to promote competitive sport	New, under way	DCMS
	Produce guidance on public health for schools, colleges and further education establishments	New, proposed	DH/DfE
	Introduce a significant pupil premium for disadvantaged pupils (CC)	New, under way	DfE
	Determine appropriate steps to protect playing fields, including improvement and protection as part of the London 2012 mass participation sports legacy	New, under way	DCMS
	Consider whether action can be taken to improve the energy efficiency, accessibility and adaptability of new homes	New, proposed	CLG
	Support sustainable travel initiatives (CC), including the new Sustainable Transport Fund	Ongoing and new	DfT
	Introduce a mass participation/community sport Olympic legacy programme	New, under way	DCMS
	Introduce a 'Green Deal' to support home energy improvements (CC)	New, proposed	DECC
	Produce practical guidance to support community groups in ownership of public spaces and community assets	New, under way	CLG
	Develop, with CLG, proposals for a new designation to protect green areas of particular importance to local communities	New	Defra
	Through the National Planning Policy Framework, explore how national planning policy might consider issues of health and wellbeing	New	CLG
	Set up an inter-ministerial working group to tackle the complex causes of homelessness	New, under way	CLG
	The Coalition Government made a commitment to train 5,000 community organisers over the course of this Parliament. They will be independent of government and led by the needs of their local community (CC)	New	Cabinet Office
	Abolish the default retirement age (CC)	New, under way	DWP
	Protect key benefits for older people (CC)	Ongoing	DWP

Mental health objective	**Action**	**Status**	**Owner**
Objective 1 (continued)	Continue the Active at 60 programme	Ongoing	DWP
	Work with the Fitness Industry Association to explore ways of utilising spare capacity in their facilities to offer activities for older people	New, proposed	DWP
	Explore potential to develop a social isolation toolkit	New, proposed	DWP
	Avoid significant adverse impacts on health and quality of life through the effective management of noise,* as set out in the Government's Noise Policy Statement for England (www.defra.gov.uk/environment/quality/noise/policy/index.htm)	Ongoing	Defra
	Ensure that the interests of people, businesses and communities in rural areas are fully and fairly recognised in all government policies and programmes and that rural communities themselves are free and able to address their own needs through locally driven initiatives	Ongoing	Defra

Mental health objective	Action	Status	Owner
Objective 2 **More people with mental health problems will recover** *More people will have a good quality of life – greater ability to manage their own lives, stronger social relationships, a greater sense of purpose, improved chances in education and employment and a suitable and stable place to live*	Extend psychological therapies to children and young people, those with serious mental illness, older people and those with medically unexplained symptoms	New, under way	DH
	Publish the MoJ Green Paper on improved mental health for offenders	Under way	DH/MoJ
	Increase access to personal health budgets to people with mental health budgets	New	DH
	Commission an independent review of DWP's specialist disability employment programmes	Under way, due to report summer 2011	DWP
	New Offender Personality Disorder Plan	Planned for consultation early 2011	DH/MoJ
	Carry out welfare reform, including the Universal Credit, the Work Programme and Work Choice (CC)	New, under way	DWP
	Reinvigorate and reform informal adult and community learning to support the Big Society and reach out to those most in need of help	Under way	BIS
	Consider next steps for the Carers Strategy	Under way	DH/DWP/BIS/DfE/CLG/GEO
	Help elderly people to live at home for longer, through solutions such as home adaptations and community support programmes (CC)	Ongoing	DH/CLG
	Maintain preventative housing programmes: Supporting People, Disabled Facilities Grant and Decent Homes	Ongoing	CLG
	Encourage data sharing between A&E and other partners to identify violence	New, proposed	Home Office/DH
	Increase the number of rape crisis centres and put them on a sustainable footing	Ongoing and new	MoJ
	Improve mental health of service personnel and veterans	Ongoing and new	MoD/DH

Mental health objective	**Action**	**Status**	**Owner**
Objective 3 **More people with mental health problems will have good physical health** *Fewer people with mental health problems will die prematurely, and more people with physical ill health will have better mental health*	Food policy, for instance development of Government Buying Standards for food which will seek to improve nutritional standards in public sector catering services as well as their sustainability	New, under way	Defra
	Changes to alcohol licensing and pricing (CC)	New, under way	Home Office
	Work with the Fitness Industry Association to explore ways of utilising spare capacity in their facilities to offer activities for older people	New, proposed	DWP
	Act on the various commitments in the public health White Paper to improve physical health, including that of people with mental health problems	New	DH and other departments
	Develop a Tobacco Control Plan	Planned for early 2011	DH
	Develop a long-term conditions (LTC) strategy to improve health and wellbeing of people with LTCs, including those with severe mental health conditions (more at risk of developing another LTC) and those with an LTC such as diabetes who have depression, anxiety and/or other emotional problems. Key strands are supporting people to self-care, and increasing choices to meet wider holistic needs through personalised care planning	Under way	DH
	Develop an Alcohol Plan	Planned for 2011	DH
	Publish a Public Health White Paper follow-up document on obesity	Planned for spring 2011	DH

Mental health objective	Action	Status	Owner
Objective 4 **More people will have a positive experience of care and support** *Care and support, wherever it takes place, will offer access to timely, evidence-based interventions and approaches that give people the greatest choice and control over their own lives, in the least restrictive environment*	Implement the recommendations of *A Vision for Adult Social Care: Capable communities and active citizens* (2010)	Ongoing	DH
	Implement the recommendations of *Quality Outcomes for People with Dementia: Building on the work of the National Dementia Strategy* (September 2010)	Ongoing	DH
	Refreshed Carers Strategy *Recognised, Valued and Supported: Next steps for the Carers Strategy* (2010)	Ongoing	DH
	Implement the Equality Act 2010	Ongoing	All
	Abolish the default retirement age (CC)	New, under way	DWP
	Protect key benefits for older people (CC)	Ongoing	DWP
Objective 5 **Fewer people will suffer avoidable harm** *People receiving care and support will have confidence that the services they use are of the highest quality and at least as safe as any other public service*	Publish the MoJ Green Paper on improved mental health for offenders	Under way	DH/MoJ
	Encourage data sharing between A&E and other partners to identify violence	New, proposed	Home Office/DH
	Increase the number of rape crisis centres	Ongoing and new	MoJ
	Implement recommendations of *Call to End Violence Against Women and Girls* (November 2010)	New and under way	Home Office
	Develop a new national suicide prevention strategy	Planned for spring 2011	DH and across government

Mental health objective	Action	Status	Owner
Objective 6 **Fewer people will experience stigma and discrimination** *Public understanding of mental health will improve and, as a result, negative attitudes and behaviours to people with mental health problems will reduce*	Implement the Equality Act 2010	Under way	All
	Include mental health as an intrinsic aspect of wellbeing within *Healthy Lives, Healthy People* (the public health White Paper), and related cross-government actions	Under way	All
	Work with Time to Change and other partners to reduce stigma for people of all ages and backgrounds	Under way	DH/All
	Work with Time to Change to agree the best ways to assess improvements in attitudes to mental health over the lifetime of this strategy, including an annual attitudes survey	Under way	DH/All

ANNEX C: GLOSSARY

At-risk mental state	A state in which a person may have brief or slight symptoms of psychosis, but is not so seriously affected by the symptoms that they can be said to have a major mental illness.
Bipolar disorder	A severe mental illness with a long course, usually characterised by episodes of depressed mood alternating with episodes of elated mood and increased activity (mania or hypomania). However, for many people the predominant experience is of low mood. In its more severe forms, bipolar disorder is associated with significant impairment of personal and social functioning.
Care Quality Commission	The independent regulator of health and social care in England. It regulates care provided by the NHS, local authorities, private companies and voluntary organisations.
Cognitive behavioural therapy	A type of therapy that aims to help people manage their problems by changing how they think ('cognitive') and act ('behavioural'), which can help them to feel better about life.
Commissioning	The process of assessing the needs of a local population and putting in place services to meet those needs.
GP consortia	Groups of GPs that will in future lead the commissioning of most healthcare services across England. GP consortia are to be statutory bodies accountable for commissioning.
Health of the Nation Outcome Scales	The most widely used routine clinical outcome measure employed by English mental health services, these scales measure behaviour, impairment, symptoms and social functioning. They form part of the English Mental Health Minimum Dataset.
Health Premium	A component of the new funding mechanism for public health that will reflect deprivation and reward progress against health improvement outcomes in local areas.

Improving Access to Psychological Therapies	A programme that aims to improve access to evidence-based psychological therapies in the NHS through an expansion of the workforce and services.
Joint Strategic Needs Assessment	An assessment that provides an objective analysis of the current and future health and wellbeing needs of local adults and children, bringing together a wide range of quantitative and qualitative data, including user views. Up until now, each area's assessment has been produced by the local authority in collaboration with the primary care trust. GP consortia and local authorities, including directors of public health, will in future have an obligation to prepare the assessment, and to do so through the arrangements made by their local health and wellbeing board.
Medically unexplained symptoms	Persistent physical complaints that do not have a readily recognisable medical cause. The pain, worry and other symptoms are nonetheless real and cause distress. People of all ages with medically unexplained symptoms present frequently to the NHS. Contacts with primary care clinicians may be at least 50% more frequent per person than in the general population, and they may also have up to 33% more secondary care consultations.
Mental capital	The entirety of a person's cognitive and emotional resources. It includes their cognitive ability, how flexible and efficient they are at learning, and their 'emotional intelligence', such as their social skills and resilience in the face of stress. It therefore conditions how well an individual is able to contribute effectively to society, as well as their ability to enjoy a high quality of life.
Mental disorder	A broad term covering mental illness, learning disability, personality disorder and substance misuse. It is more formally defined as 'mental illness, arrested or incomplete development of mind, psychopathic disorder and any other disorder or disability of mind'.
Mental health	Good or positive mental health is more than the absence or management of mental health problems; it is the foundation for wellbeing and effective functioning both for individuals and for their communities.
Mental Health Minimum Dataset	A nationally defined framework of data on adult patients, held locally by mental health trusts. It is designed to show in detail the patterns of care received by patients looked after by specialist mental health care providers in England.

Mental health problem	A phrase used in this strategy as an umbrella term to denote the full range of diagnosable mental illnesses and disorders, including personality disorder. Mental health problems may be more or less common and acute or longer lasting, and may vary in severity. They manifest themselves in different ways at different ages and may present as behavioural problems (for example, in children and young people). Some people object to the use of terms such as 'mental health problem' on the grounds that they medicalise ways of thinking and feeling and do not acknowledge the many factors that can prevent people from reaching their potential. We recognise these concerns and the stigma attached to mental ill health; however, there is no universally acceptable terminology that we can use as an alternative.
Mental illness	A term generally used to refer to more serious mental health problems that often require treatment by specialist services. Such illnesses include depression and anxiety (which may also be referred to as common mental health problems) as well as schizophrenia and bipolar disorder (also sometimes referred to as severe mental illness). Conduct disorder and emotional disorder are the commonest forms of childhood mental illness.
Multisystemic Therapy	An evidence-based, intensive family- and community-based intervention that helps high-risk young people to modify their conduct or address their emotional problems and improves long-term outcomes.
National Confidential Inquiry into Suicide and Homicide by People with Mental Illness	A research project largely funded by the National Patient Safety Agency. Other funders are the Scottish Government and the Northern Ireland Department of Health, Social Services and Public Safety.
National Institute for Health and Clinical Excellence	An independent organisation that provides advice and guidelines on the cost and effectiveness of drugs and treatments.
NHS Commissioning Board	A proposed new body that will have powers devolved to it directly from the Secretary of State for Health. It will be responsible for allocating and accounting for NHS resources and for supporting the GP consortia and holding them to account in terms of outcomes, financial performance, and fairness and transparency in the performance of their functions.

Personality disorder	Any disorder in which an individual's personal characteristics cause regular and long-term problems in the way they cope with life and interact with other people and in their ability to respond emotionally.
Population mental health	A measure of the proportion of the population with different levels of mental health at any one time. The spectrum ranges from mentally ill and languishing through to moderately mentally healthy and flourishing.
Protected characteristics	Characteristics against which the Equality Act 2010 prohibits discrimination, including age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation.
Psychosis	Psychosis affects a person's mind and causes changes to the way that they think, feel and behave. A person who experiences psychosis may be unable to distinguish between reality and their imagination. They may have hallucinations or delusions. Psychosis is not a condition in itself; it is a symptom of other conditions. The most common causes of psychosis are mental health conditions such as schizophrenia or bipolar disorder.
Public Health England	A new body which, subject to passage of the Health and Social Care Bill, will be established within the Department of Health in 2012 and will set the overall Outcomes Framework for public health. It will be accountable to the Secretary of State for Health.
Public mental health	The art and science of promoting wellbeing and equality and preventing mental ill health through population-based interventions to: • reduce risk and promote protective, evidence-based interventions to improve physical and mental wellbeing; and • create flourishing, connected individuals, families and communities.
Quality Accounts	Reports on the quality of services published annually by providers of NHS care. Quality Accounts are intended to enhance accountability to the public.
Quality Standards	A set of specific, concise statements that act as markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions, and published by NICE.

Recovery	This term has developed a specific meaning in mental health that is not the same as, although it is related to, clinical recovery. It has been defined as: 'A deeply personal, unique process of changing one's attitudes, values, feelings, goals skills and/or roles. It is a way of living a satisfying, hopeful and contributing life, even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life.'[95]
Resilience	An important aspect of wellbeing and mental health: the ability to cope with adverse circumstances, either as an individual or in a community.
Schizophrenia	A major psychiatric disorder, or cluster of disorders, characterised by psychotic symptoms that alter a person's perceptions, thoughts, affect and behaviour. Each person with the disorder will have a unique combination of symptoms and experiences.
Severe (or serious) mental illness	More severe and long-lasting mental illness associated with functional impairment. Someone with a severe or serious mental illness may nevertheless also have long periods when they are well and are able to manage their illness.
Tariff	In relation to Payment by Results, the calculated price for a unit of healthcare activity.
Wellbeing	(Sometimes referred to as mental wellbeing or emotional wellbeing.) For the purposes of this strategy the following definition has been developed: 'A positive state of mind and body, feeling safe and able to cope, with a sense of connection with people, communities and the wider environment.'

ANNEX D: LIST OF ACRONYMS

AIE	Analysis of the Impact on Equality
BIS	Department for Business, Innovation and Skills
BME	black and minority ethnic
CAMHS	child and adolescent mental health services
CBT	cognitive behavioural therapy
CC	Coalition commitment
CLG	Department for Communities and Local Government
CQC	Care Quality Commission
DCMS	Department for Culture, Media and Sport
DECC	Department of Energy and Climate Change
Defra	Department for Environment, Food and Rural Affairs
DfE	Department for Education
DfT	Department for Transport
DH	Department of Health
DWP	Department for Work and Pensions
HoNOS	Health of the Nation Outcome Scales
HSE	Health and Safety Executive
IAPT	Improving Access to Psychological Therapies
JSNA	Joint Strategic Needs Assessment
LTC	long-term (physical health) condition
MoD	Ministry of Defence
MoJ	Ministry of Justice
MST	Multisystemic Therapy

NICE	National Institute for Health and Clinical Excellence
NIHR	National Institute for Health Research
ONS	Office for National Statistics
QIPP	Quality, Innovation, Productivity and Prevention
QOF	Quality and Outcomes Framework
TaMHS	Targeted Mental Health in Schools

ANNEX E: REFERENCES

1 Department of Health (2010) *Healthy Lives, Healthy People: Our strategy for public health in England*, available at: http://tinyurl.com/HealthyLivesHealthyPeople

2 WHO (2008) *The Global Burden of Disease: 2004 update*, available at: www.who.int/healthinfo/global_burden_disease

3 The Prince's Trust (2010) *Macquarie Youth Index*, available at: http://tinyurl.com/youth-index-2010

4 McCrone P, Dhanasiri S, Patel A et al. (2008) *Paying the Price: The cost of mental health care in England*. London: King's Fund, 220–226.

5 McManus S, Meltzer H, Brugha T et al. (2009) *Adult Psychiatric Morbidity in England, 2007: Results of a household survey*. Leeds: NHS Information Centre for Health and Social Care.

6 Green H, McGinnity A, Meltzer H et al. (2005) *Mental Health of Children and Young People in Great Britain, 2004.* Basingstoke: Palgrave Macmillan.

7 Kim-Cohen J, Caspi A, Moffitt T et al. (2003) Prior juvenile diagnoses in adults with mental disorder. *Archives of General Psychiatry* 60: 709–717; Kessler R, Berglund P, Demler O et al. (2005) Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry* 62: 593–602.

8 Kessler R and Wang P (2007) The descriptive epidemiology of commonly occurring mental disorders in the United States. *Annual Review of Public Health* 29: 115–129.

9 Hawton K, Rodham K, Evans E and Weatherall R (2002) Deliberate self harm in adolescents: self report survey in schools in England. *British Medical Journal* 325: 1207–1211.

10 Andrews G, Poulton R and Skoog I (2005) Lifetime risk of depression: restricted to a minority or waiting for most? *British Journal of Psychiatry* 187: 495–496.

11 Gavin N, Gaynes B, Lohr K et al. (2005) Perinatal depression: a systematic review of prevalence and incidence. *Obstetrics and Gynaecology* 106: 1071–1083.

12 Rees S (2009) *Mental Ill Health in the Adult Single Homeless Population: A review of the literature*. London: Crisis and Public Health Resource Unit.

13 Kim-Cohen J, Caspi A, Moffitt T et al. (2003) Prior juvenile diagnoses in adults with mental disorder. *Archives of General Psychiatry* 60: 709–717; Kessler R, Berglund P, Demler O et al. (2005) Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry* 62: 593–602.

14 Kessler R and Wang P (2007) The descriptive epidemiology of commonly occurring mental disorders in the United States. *Annual Review of Public Health* 29: 115–129.

15 McManus S, Meltzer H, Brugha T et al. (2009) *Adult Psychiatric Morbidity in England, 2007: Results of a household survey*. NHS Information Centre for Health and Social Care.

16 Brown S, Kim M, Mitchell C and Inskip H (2010) Twenty-five year mortality of a community cohort with schizophrenia. *British Journal of Psychiatry* 196: 116–121; Parks J, Svendsen D, Singer P et al. (2006) *Morbidity and Mortality in People with Serious Mental Illness*, 13th technical report. Alexandria, Virginia: National Association of State Mental Health Program Directors.

17 Chevalier A and Feinstein L (2006) *Sheepskin or Prozac: The causal effect of education on mental health*. Discussion paper. London: Centre for Research on the Economics of Education, London School of Economics, available at: http://cee.lse.ac.uk/cee%20dps/ceedp71.pdf

18 Meltzer H, Bebbington P, Brugha T et al. (2010) Job insecurity, socio-economic circumstances and depression. *Psychological Medicine* 40(8): 1401–1407.

19 McManus S, Meltzer H, Brugha T et al. (2009) *Adult Psychiatric Morbidity in England, 2007: Results of a household survey*. NHS Information Centre for Health and Social Care.

20 Rees S (2009) *Mental Ill Health in the Adult Single Homeless Population: A review of the literature*. London: Crisis and Public Health Resource Unit.

21 Cooper R, Boyko C and Codinhoto R (2008) DR2 – the effect of the physical environment on mental wellbeing. *Mental Capital and Wellbeing Project*. London: Government Office for Science, Foresight, available at: www.foresight.gov.uk/OurWork/ActiveProjects/Mental%20Capital/ProjectOutputs.asp

22 McManus S, Meltzer H, Brugha T et al (2009) Adult psychiatric morbidity in England, 2007. Results of a household survey. Health and Social Care Information Centre, Social Care Statistics

23 Government Office for Science (2008) *Mental Capital and Wellbeing: Making the most of ourselves in the 21st century – Final Project Report*, available at: http://tinyurl.com/ForesightReportMentalCapital

24 Health and Safety Executive (2009) *How to Tackle Work-related Stress: A guide for employers on making the Management Standards work*, available at: www.hse.gov.uk/pubns/indg430.pdf

25 WHO (2008) *The Global Burden of Disease: 2004 update*, available at: www.who.int/healthinfo/global_burden_disease

26 Department of Health (2009) *Departmental Report 2009: The Health and Personal Social Services Programmes*, available at: www.official-documents.gov.uk/document/cm75/7593/7593.pdf

27 McCrone P, Dhanasiri S, Patel A et al. (2008) *Paying the Price: The cost of mental health care in England*. London: King's Fund, 220–226.

28 Department of Health (2009) *Departmental Report 2009: The Health and Personal Social Services Programmes*, available at: www.official-documents.gov.uk/document/cm75/7593/7593.pdf

29 Sainsbury Centre for Mental Health (2003) *The Economic and Social Costs of Mental Illness*. Policy paper 3, available at: www.centreformentalhealth.org.uk/pdfs/costs_of_mental_illness_policy_paper_3.pdf

30 Centre for Mental Health (2010) *The Economic and Social Costs of Mental Health Problems in 2009/10*, available at: www.centreformentalhealth.org.uk/pdfs/Economic_and_social_costs_2010.pdf

31 Sainsbury Centre for Mental Health (2007) Mental health at work. Developing the business case, available at: http://www.scmh.org.uk/publications/publications_list.aspx?SortID=e

32 Department for Work and Pensions (2010) Statistical Summaries, available at: http://campaigns.dwp.gov.uk/asd/index.php?page=statistical_summaries

33 Department for Communities and Local Government (2010) *Decentralisation and the Localism Bill: An essential guide*, available at: www.communities.gov.uk/documents/localgovernment/pdf/1793908.pdf

34 Home Office (2010) *Drug Strategy 2010 – Reducing demand, restricting supply, building recovery: Supporting people to live a drug free life*, available at: www.homeoffice.gov.uk/publications/drugs/drug-strategy/drug-strategy-2010?view=Binary

35 HM Government (2010) *A Call to End Violence Against Women and Girls*, available at: www.homeoffice.gov.uk/publications/crime/call-end-violence-women-girls/vawg-paper?view=Binary

36 Department for Education (2010) *Green Paper: Children and young people with special educational needs and disabilities – Call for views*, available at: http://tinyurl.com/SENDResponses

37 Ministry of Justice (2010) *Breaking the Cycle: Effective punishment, rehabilitation and sentencing of offenders*, available at: www.justice.gov.uk/consultations/docs/breaking-the-cycle.pdf

38 Department of Health (2010) *Equity and Excellence: Liberating the NHS*, available at: http://tinyurl.com/EquityExcellenceLiberatingNHS

39 Department of Health (2010) *A Vision for Adult Social Care: Capable communities and active citizens*, available at: www.dh.gov.uk/en/Aboutus/Features/DH_121664

40 Anthony WA (1993) Recovery from mental illness: the guiding vision of the mental health system in the 1990s. *Psychosocial Rehabilitation Journal* 16(4): 11–23.

41 See, for example, Friedli L (2009) *Mental Health, Resilience and Inequalities*. Mental Health Foundation and World Health Organization (WHO) Europe, available at: www.euro.who.int/document/e92227.pdf

42 Department of Health (2010) *Healthy Lives, Healthy People: Transparency in outcomes – Proposals for a public health outcomes framework*, available at: http://tinyurl.com/PublicHealthOutcomesConsult

43 Department of Health (2010) *Transparency in Outcomes: A framework for adult social care – A consultation on proposals*, available at: http://tinyurl.com/SocialCareOutcomesConsult

44 Clark C, Candy B, Stansfield S (2006) A systematic review on the effect of the built and physical environment on mental health. Centre for Psychiatry, Wolfson Institute of Preventive Medicine, Queen Mary's School of Medicine and Dentistry, University of London.

45 Mykletun A, Bjerkeset O, Overland S et al (2009) Levels of anxiety and depression as predictors of mortality: the HUNT study. British Journal of Psychiatry, 195, 118-125.

46 Hemingway H and Marmot M (1999) Evidence based cardiology. Psychosocial factors in the aetiology and prognosis of coronary heart disease: systematic review of prospective cohort studies. *British Medical Journal* 318: 1460–1467; Nicholson A, Kuper H and Hemingway H (2006) Depression as an aetiologic and prognostic factor in coronary heart disease: a meta-analysis of 6362 events among 146 538 participants in 54 observational studies. *European Heart Journal* 27(23): 2763–2774.

47 Parks J, Svendsen D, Singer P et al. (2006) *Morbidity and Mortality in People with Serious Mental Illness*, 13th technical report. Alexandria, Virginia: National Association of State Mental Health Program Directors.

48 De Hert M, Dekker JM, Wood D et al (2009) Cardiovascular disease and diabetes in people with severe mental illness. Position statement from the European Psychiatric Association. European Psychiatry. http://www.easd.org/easdwebfiles/statements/EPA.pdf

49 McManus S, Meltzer H and Campion J (2010) Cigarette smoking and mental health in England. Data from the Adult Psychiatric Morbidity Survey. National Centre for Social Research, available at: www.natcen.ac.uk/media/601275/smoking_and_mental_health_-_final_report_revised%20and%20final.pdf

50 Green H, McGinnity A, Meltzer H et al. (2005) *Mental Health of Children and Young People in Great Britain*, *2004*. Basingstoke: Palgrave Macmillan.

51 NICE (2009) *Depression in Adults with a Chronic Physical Health Problem: Treatment and management*, NICE Clinical Guideline 91, available at: www.nice.org.uk/nicemedia/pdf/CG91NICEGuideline.pdf

52 Parry-Langdon N (ed) (2008) *Three Years On: Survey of the development and emotional well-being of children and young people*. Newport: Office for National Statistics.

53 NICE (2009) *Depression in Adults with a Chronic Physical Health Problem: Treatment and management*, NICE Clinical Guideline 91, available at: www.nice.org.uk/nicemedia/pdf/CG91NICEGuideline.pdf

54 NHS Confederation Mental Health Network and National Mental Health Development Unit (2009) *Acute Care Declaration*, available at: www.acutecareprogramme.org.uk/silo/files/acute-care-declaration-leaflet.pdf

55 Fortune S and Hawton K (2005) Suicide and deliberate self-harm in children and adolescents. *Current Paediatrics* 15: 575–580.

56 Government Office for Science (2008) *Mental Capital and Wellbeing: Making the most of ourselves in the 21st century – Final project report*, available at: http://tinyurl.com/ForesightReportMentalCapital

57 Department of Health (2010) *New Horizons – Confident communities, brighter futures: A framework for developing well-being*, available at: http://tinyurl.com/ConCommunitiesBrighterFutures

58 Putting People First (2010) *Think Local, Act Personal: Next steps for adult social care*, available at: http://tinyurl.com/ThinkLocalActPersonal

59 Department of Health (2010) *Recognised, Valued and Supported: Next steps for the Carers Strategy*, available at: http://tinyurl.com/NextStepsCarersStrategy

60 The Princess Royal Trust for Carers and National Mental Health Development Unit (2010) *Triangle of Care – Carers included: A guide to best practice in acute mental health care*, available at: http://its-services.org.uk/silo/files/triangle-of-care-carers-included.pdf

61 Brugha T, Weich S, Singleton N et al. (2005) Primary group size, social support, gender and future mental health status in a prospective study of people living in private households throughout Great Britain. *Psychological Medicine*, 35(5): 705–714.

62 Melzer D, Fryers T and Jenkins R (2004) *Social Inequalities and the Distribution of Common Mental Disorders*. Maudsley Monograph 44. Hove: Psychology Press.

63 Brown S, Nesse R, Vonokur A and Smith D (2003) Providing social support may be more beneficial than receiving it: results from a prospective study of mortality. *Psychological Science* 14(4): 320–327.

64 Rabiner D, Scheffler S, Koetse E et al. (2003) The impact of the senior companion program on quality of life outcomes for frail older adults and their families. *Home Health Care Services Quarterly* 22(4): 1–26.

65 Wheeler J, Gorey K and Greenblatt B (1998) The beneficial effects of volunteering for older volunteers and the people they serve: a meta-analysis. *International Journal of Aging and Human Development* 47(1): 69–79.

66 Department of Health (2010) *Practical Approaches to Improving the Lives of Disabled and Older People through Building Stronger Communities*, available at: http://tinyurl.com/CommunityCapacity

67 Business in the Community (2009) Emotional Resilience Toolkit, available at: www.bitc.org.uk/resources/publications/emotional_resilience.html; Health and Safety Executive Management Standards, available at: www.hse.gov.uk/stress/standards/

68 Boorman S (2009) *NHS Health and Well-being: Final Report.* Department of Health, available at: http://tinyurl.com/NHSHealthandWellbeing

69 Mind (2010) *Taking Care of Business: Employers' guide to mentally healthy workplaces*, available at: www.mind.org.uk/assets/000/8387/EMPLOYERS_LZ.pdf

70 Department of Health (2010) *Achieving Equity and Excellence for Children*, available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119449

71 Kennedy I (2010) *Getting It Right for Children and Young People: Overcoming cultural barriers in the NHS so as to meet their needs*, available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119445

72 Department for Education (2010) *Monitoring and Evaluation of Family Intervention Projects to March 2010*. Statistical Release, available at: www.education.gov.uk/rsgateway/DB/STR/d000956/osr09-2010.pdf

73 Home Office (2010) *Drug Strategy 2010 – Reducing demand, restricting supply, building recovery: Supporting people to live a drug free life*, available at: www.homeoffice.gov.uk/publications/drugs/drug-strategy/drug-strategy-2010?view=Binary

74 Green H, McGinnity A, Meltzer H et al. (2005) *Mental Health of Children and Young People in Great Britain, 2004.* Basingstoke: Palgrave Macmillan.

75 Blonk R, Brenninkmeijer V, Lagerveld S and Houtman I (2006) Return to work: a comparison of two cognitive behavioural interventions in cases of work-related psychological complaints among the self-employed. *Work and Stress* 20(2): 129–144; Lagerveld S, Blonk R, Brenninkmeijer V and Schaufeli W (2010) Return to work among employees with mental health problems: development and validation of a self-efficacy questionnaire. *Work and Stress* 24(4): 359–375.

76 Bradley K (2009) *The Bradley Report: Lord Bradley's review of people with mental health problems or learning disabilities in the criminal justice system*, available at: http://tinyurl.com/TheBradleyReport

77 Ministry of Justice (2010) *Breaking the Cycle: Effective punishment, rehabilitation and sentencing of offenders*, available at: www.justice.gov.uk/consultations/docs/breaking-the-cycle.pdf

78 Medical Research Council (2010) *MRC Review of Mental Health Research – Report of the Strategic Review Group,* available at: www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC006848

79 National Institute for Mental Health in England, Barts and The London School of Medicine and Department of Health (2009) *Outcomes Compendium: Helping you select the right tools for best mental health care practice in your field*, available at: http://tinyurl.com/OutcomesCompendium

80 Marmot M (2010) *Fair Society, Healthy Lives: Strategic review of health inequalities in England post-2010*, available at: www.marmotreview.org

81 See NMHDU Fact File 5, available at: www.nmhdu.org.uk

82 Godfrey M, Townsend J, Surr C et al. (2005) *Prevention and Service Provision: Mental health problems in later life*. Leeds: Institute of Health Sciences and Public Health Research, Leeds University, and Division of Dementia Studies, Bradford University.

83 Craig R and Mindell J (eds) (2007) *Health Survey for England 2005: Health of older people*. Leeds: NHS Information Centre.

84 Chew-Graham C, Burns A and Baldwin R (2004) Treating depression in later life: we need to implement the evidence that exists. *British Medical Journal* 329: 181–182.

85 Department of Health (2010) *Quality Outcomes for People with Dementia: Building on the work of the National Dementia Strategy*, available at: http://tinyurl.com/DementiaStrategyImplementation

86 Department of Health (2010) *Race Equality Action Plan: A five year review*, available at: www.nmhdu.org.uk/news/race-equality-action-plan-a-five-year-review/

87 Department of Health (2010) *Implementing 'Fulfilling and Rewarding Lives': Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy*, available at: http://tinyurl.com/AutismStatutoryGuidance

88 Equality and Human Rights Commission (2010) *How Fair is Britain? Equality, human rights and good relations in 2010. The First Triennial Review*, available at: http://tinyurl.com/EHRCTriennialReview

89 Williams J and Paul J (2008) *Informed Gender Practice: Mental health acute care that works for women.* London: National Institute for Mental Health in England; National Mental Health Development Unit (2010) *Working towards Women's Well-being: Unfinished business*, available at: www.nmhdu.org.uk/silo/files/working-towards-womens-wellbeing-unfinished-business.pdf

90 Wilkins D (2010) *Untold Problems: A review of the essential issues in the mental health of men and boys*. Men's Health Forum and National Mental Health Development Unit.

91 Wilkins D and Kemple M (2011) *Delivering Male: Effective practice in male mental health*. Men's Health Forum, Mind and National Mental Health Development Unit.

92 Equality and Human Rights Commission (2009) *Trans Research Review*, available at: http://tinyurl.com/EHRCTransReseachReview

93 Department of Health (2009) *Use of Resources in Adult Social Care: A guide for local authorities*, available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_107596

94 NICE (2006) *Technology Appraisals: Conduct disorder in children – parent-training/educational programmes in the management of children with conduct disorder and implementation advice*, available at: www.nice.org.uk/TA102

95 Anthony WA (1993) Recovery from mental illness: the guiding vision of the mental health system in the 1990s. *Psychosocial Rehabilitation Journal* 16(4): 11–23.

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Rapid review of Northern Ireland Health and Social Care funding needs and the productivity challenge: 2011/12-2014/15

Professor John Appleby

March 2011

John Appleby is Chief Economist at the King's Fund (www.kingsfund.org.uk) and has carried out this review as an independent expert on behalf of the Department of Health, Social Services and Public Safety. DHSSPS staff provided analytic support.

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Executive summary

The macroeconomic context and impact of the 2010 Spending Review

- The global financial crisis and ensuing recession have left national finances in considerable imbalance. Correcting an unsustainable debt and deficit position has entailed increases in taxation and severe cuts in public spending.

- BY 2014/15, the 2010 spending review plans cuts in departmental spending of around 11% in real terms (in addition to cuts in welfare benefits).

- Spending cuts have not been spread evenly, with health care in all four territories of the UK being ‘protected’ to varying degrees relative to other spending areas.

- Spending changes for personal social services over the next four years across the UK are less certain, due to local spending decisions by councils in, for example, England.

- The latest Budget for Northern Ireland suggest health and social care will receive a real cut in its budget by 2014/15 of around 2.7%. This compares to a real cut of around0.25% (more if social care is included) in England, a real cut of around 7.9% in Wales (by 2013/14) and, for next year at least, a real cut of 2.9% in Scotland (not including social care).

- All health and social care services across the UK thus face one of the most severe funding situations since the Second World War.

Funding needs for Northern Ireland 2010/11 - 2014/15

- The judgement of this review is a needs differential for Northern Ireland relative to England of +9%

- The difference in additional funding due to the choice of additional need for Northern Ireland relative to England is relatively small; every 1% additional need translates into £11 million to £15 million additional funding by 2014/15 as the additional needs factor is applied to the marginal growth in funding not the entire Northern Ireland spend.

- Using 2007/8 as a base year, updating three relative needs models used by the 2005 Appleby review and applying Wanless 2002 future funding recommendations to Northern Ireland suggests funding of between £5,327 million and £5,913 million by 2014/15 (at 2010 prices, or £5,886 million and £6,533 in cash terms) depending on the relative additional needs and Wanless scenario across all three models.

- Using 2010/11 as a base year, funding requirements in 2014/15 would be £5,067 million and £5,377 million in real terms (£5,608 million and £5,941 million in cash terms) depending on the relative additional needs and Wanless scenario across all three models

- On the basis of additional needs of +9%, required funding by 2014/15 is projected to be between £5,360 million and £5,790 million (£5,923 and £6,397 million in cash terms) depending on the Wanless scenario adopted.

The funding gap for Northern Ireland

- Compared with the latest Budget proposals for Northern Ireland, the gap with funding suggested by Wanless and a +9% needs differential will amount to between £1.1 billion and £1.5 billion depending on the Wanless scenario.

- If, however, Northern Ireland had received the same funding increases as the English NHS from 2007/8 to 2010/11 (and the equivalent SR 2010 settlement as the NHS to 2014/15) then the funding gap would be between £0.7 billion and £1.1 billion.

The productivity challenge

- Derek Wanless's funding recommendations for health care across the UK were dependent on the NHS achieving certain levels of productivity improvements. These amounted to between 12% and 20% between 2007/8 and 2014/15 depending on the Wanless scenario.

- Re-analysis of the funding gap calculations incorporating Wanless's productivity assumptions suggests -relative to the Budget for Northern Ireland - a combined funding/productivity gap of between £2 billion and £2.1 billion (on the basis of a needs differential of +9%.)

- Even if health and social care were to receive funding in line with Wanless's recommendations, this would still leave a need to achieve the productivity gains inherent in his recommended funding levels. Depending on the Wanless scenario, these would amount to between £576 million to £892 million by 2014/15 at today's prices for the +9% additional need judgement.

- Overall, the £2 billion productivity challenge facing the Health and Social Care System represents the unmet funding gap **plus** the value of the Wanless productivity assumption. It is essentially an indication in monetary terms of the additional value for money that DHSSPS would have to generate to deliver a modern, sustainable health service in 2014/15 in line with Wanless' 2002 'vision' for the system.

- A broad disaggregation of the value of the productivity gain based on Wanless's 'vision' for future health care services under his Solid Progress scenario suggests that over half the combined funding/productivity gap will need to be closed by: gains in quality, around 9% in responding to demand pressures, around 16% to improving waiting times, capital infrastructure and clinical governance and the remainder (17%) to real increases in pay and prices.

- Cutting production costs will be part of the task of achieving productivity gains - but largely as a means of freeing resources for higher value activities. However, more importantly, closing the Wanless funding gap requires improving the quality of care received by patients - improving health outcomes, reducing negatively valued attributes of care such as long waiting times etc - but within the constraints of future budgets.

System performance overview

- A system-wide measure of productivity for the Northern Ireland NHS suggests a small increase of productivity between 2005/6 and 2008/9 of just 1% - achieved largely from one year's slow down in input growth rather than growth in outputs over inputs.

- Applying England's unit HRG costs to Northern Ireland activity reveals large 'excess' costs of production: Provisional data for 2009/10 shows: Elective inpatients, 16% excess costs; non-elective inpatients, 29%; day cases, 5%. Overall, costs were around 22% higher.

- There is considerable variation across providers when applying England's unit costs to their activity. Some hospitals appear to incur more than twice the cost that would be expected if they operated at England's unit HRG costs for elective inpatients.

- The total estimated 'excess' cost for elective and non-elective inpatient and day case activity was around £126 million in 2008/9.

- Accurate comparative data on workforce productivity has been difficult to produce. However, indicative data suggests Northern Ireland produces between 17% and 30% less inpatient, outpatient, day case and A&E activity per head of HCHS staff than England.

- Northern Ireland has over 20% more acute beds than England, but these are used less intensively; throughput per bed is around 25% lower than that achieved in England. Patients also stay in hospital around 28% (1.2 days) longer than patients in England.

- Waiting lists for inpatients and outpatients are now rising rapidly since significant falls from 2006 to 2009.

- Around 5,900 patients are waiting over half a year for admission to hospital as an inpatient and over 10,000 are still waiting over half a year for their first outpatient appointment.

- Pharmaceutical costs have risen faster in Northern Ireland than anywhere else in the UK between 2006 and 2009 - net ingredient costs per head of population have risen by over 8% and are now 40% higher than in England.

- Generic dispensing continues to improve - from around 50% in 2007 to 62% in 2009. This compares to 68% in England.

SECTION 1: INTRODUCTION

Background to this review

In 2005 a review of health and social care services in Northern Ireland was carried out at the request of the (then) Finance Minister and Health and Social Services Minister (Appleby, 2005). The aim of that review was primarily to establish future funding paths for health and social care up to 2022/23 based on Sir Derek Wanless's 2002 review of future UK NHS funding applied to Northern Ireland (Wanless, 2002). The review also examined aspects of the productivity of health and social care services and the prevailing performance management system. The 2005 review made 25 recommendations - from levels of future funding and the need to measure outcomes to strategies to reduce waiting times and improve the performance management of the system as a whole (see box 1).

Box 1: Recommendations from the 2005 Appleby Review of the Northern Ireland Health and Social Care services.

1: In the light of suggested future funding (see Recommendation 3), in-year monitoring additions to health and social care budgets should cease other than in exceptional circumstances and solely on a one-off basis

2 : Over and above the need to track spending for reasons of financial probity, the main performance policy monitoring focus should be on tracking outcomes, not spending per se. A programme budgeting approach - as currently being developed in England for 23 disease/service groups- in addition to traditional accounting would be of help with this

3: Adopt HMT NAS model-based Wanless 'fully engaged scenario' projections as set out in Table 1 for now as best reasonable guide to future spending in NI

4: Further work is needed to investigate the usefulness of employing direct measures of health status (for example, as derived from instruments such as the EQ-5D) in resource allocation models

5: Future work on pan-UK resource allocation model would provide a more empirically-based answer to relative shares of resources. Such work should be open, and draw on extensive experience in the area of resource allocation models of research groups across the UK

6: If the future spending path suggested by this Review is accepted, then there needs to be some way round the implications of the Barnett Formula for health and social care if the general principle of Barnett are to be maintained and other public services in Northern Ireland are not to suffer

7: Routine collection of self-assessed health status data at population level would yield useful comparative data on population health status. In addition, the potential for routine collection of patient related outcome measures in health care services should be explored

8: On the basis of current lifestyle data, the funding recommendations based on the Wanless 'fully engaged' scenario imply considerable effort will be needed to engage the Northern Ireland population through expanded public health services and other means.

9: Further investigation is required of very high A&E use to explore reasons and find ways for reducing likely inappropriate use

Box 1: Recommendations from the 2005 Appleby Review of the Northern Ireland Health and Social Care services. (continued)

10: Detailed analysis is needed into hospital activity trends as part of a broader analysis of the dynamics of waiting times and lists

11: DHSSPS should develop a more coherent strategy towards partnership with private sector

12: Adopt a multi-pronged long term strategy to reducing waiting times, including long term targets (with milestones) backed by strong incentives

13: Investigate ways to reduce unit cost variations through incentive mechanisms such as tariff-based activity payment/budget setting systems

14: Further investigation is needed to explore possible of reasons for high unit costs at the Royal and Green Park Trusts

15: Investigate scope for further reductions in length of stay and avoidance of admission to hospital

16: Aim in medium term to use outcome-based productivity measures.

17: An assessment should be carried out on the implementation of the GMS contract in Northern Ireland to examine whether the actual improvements in quality outweigh the cost. In light of the finding, the GMS contract should be revised as far as practicable

18: New mechanisms involving greater use of sanctions are needed to tackle high prescribing costs and to encourage greater use of generic drugs.

19: The integration of health & social services should be re-examined with an initial first stage being the implications of ring fencing of funding for social services from the acute sector. There should however be scope for financial sanctions when inefficiency in one part of the system impacts negatively on another e.g. lack of social services provision causing delayed discharge from hospital.

20: Contracting for services from independent/voluntary organisations should be reviewed to consider whether it can be placed on a more strategic basis.

21: Further investigation is required of possible reasons for relatively low labour productivity

22: Health and social care workers in Northern Ireland should formally come under the remit of the relevant GB Pay Review Bodies: this will enable the Government's local pay policy to be implemented on an equal basis in Northern Ireland to the rest of the UK.

23: There is a need to develop an explicit performance management system with rewards and sanctions which provide enough 'bite' to encourage change and innovation in the health and social care system. There are many options for the types of incentives that could be introduced and their design for Northern Ireland. There should however be a commitment to such reform coupled with further investigation of how incentives can be strengthened.

24: Separation of the tasks of service provision and commissioning is an important factor in sharpening incentives. However, the most appropriate structures (e.g. single pan-NI commissioner; devolved GP commissioning etc) needs further investigation.

25: Alongside changes in the performance management system, there is a need to explore the development of a more transparent priority setting process at national level, together with an explicit 'NHS Plan for Northern Ireland' which sets out outcome-based targets linked to new spending paths.

Two key outcomes of the 2005 Review which in particular concern this present review are the estimates made of the relative funding needs for health and social care in Northern Ireland and the need to improve productivity (see Box 2).

Box 2: Future funding and performance: Summary from the findings of the 2005 Appleby Review

Based on an assessment of a 7% greater level of need for health and social care services in Northern Ireland compared with England, the 2005 Review suggested a number of possible funding paths to 2022/23 (see Table 1)

Table 1: Health And Social Care Spending Projections for Northern Ireland

	2002-03	2007-08	2012-13	2017-18	2022-23
Total NI Health & Social Care Spending (£ billion 2004-05 prices)					
Solid Progress	2.7	3.7	4.7	5.5	6.2
Slow Uptake	2.7	3.8	4.9	6.0	7.1
Fully Engaged	2.7	3.7	4.6	5.3	6.0
Average annual real growth in NI Health and Social Care spending (per cent)					
Solid Progress		6.8	4.6	3.1	2.7
Slow Uptake		7.0	5.4	4.0	3.5
Fully Engaged		6.8	4.3	2.8	2.4

However, there was extensive evidence of lower levels of productivity in Northern Ireland:

- Hospital activity per member of staff is 19% **lower** than the UK average.
- Hospital activity per pound of health spend is 9% **lower** than the UK average
- Hospital activity per available bed is 26% **lower** than in England
- The unit cost of procedures is 9% **higher** in NI than England with day case unit costs 9% **lower** and elective inpatient unit costs 12.6% **higher**.
- There are significant **variations** in unit costs between trusts
- Day case rates are **higher** than the UK average and have risen significantly since 1990/91.
- Length of stay has remained broadly unchanged over the past five years.
- Average unit prescribing costs are nearly 30% **higher** in Northern Ireland than in England
- Nearly one in ten of the total Northern Ireland population is currently waiting to attend for a first outpatient appointment.

Since 2005 much has changed however. The macroeconomic environment has been in upheaval with the catastrophe of the global banking crisis and the ensuing recession. The consequent need to manage down national debt and to realign government income and expenditure will have a significant impact on public spending. This became evident in the 2010 Spending Review which laid out a very difficult financial settlement in England (with consequent knock on effects for Northern Ireland). While the NHS in England has been treated relatively favourably with respect to other spending departments, virtually zero real growth over the next four years represents its worst allocation since 1948.

Similarly, the proposed budget settlement for health and social care in Northern Ireland, while comparatively favourable, suggests a real reduction in spending to 2014/15 of around 2.7% (about 0.7% per year on average). Over the last six years there have also been changes in the performance and management arrangements of Northern Ireland's health and social care services.

Given these changes and the unprecedented financial position over the next four years, it has been considered timely by DHSSPS to commission a rapid review of some selected recommendations and issues covered by the 2005 review. The terms of reference for this new review are set out below.

Terms of reference

In broad terms, the scope of the review will be the coverage of the 2005 review which considered both the needs and effectiveness of health and social care in Northern Ireland. For practical reasons and given the dominance of the immediate financial position, this review will focus on the following however:

1. An update of 2005 Review's assessment of relative need for Health and Social Care services in Northern Ireland

2. Estimation of the current and future funding 'gap' (between what is needed to run a fit for purpose health and social care system and what is available)

3. A comparison between the funding gap and the identifiable productivity gap within the system.

4. An outline of the opportunities available to fill the productivity gap through actions in different parts of the system.

5. (If time permits) an outline of the ways information systems can support this process.

Structure of report

The next section (2) briefly, but in a bit more detail, sets out the macroeconomic situation and the current position on public finances following last autumn's Spending Review including DFP’s current budget proposals for 2011/12 to 2014/15. Section 3 reports on updates of three of the models used in the 2005 review to obtain estimates of future funding for health and social care in Northern Ireland based on Northern Ireland’s ‘fair shares’ of the growth in future UK health and social care funding recommended by the 2002 Wanless Review.

The following section (4) provides various estimates of the ‘gap’ in funding using the estimates of future funding needs from section 3 set against a number of actual future funding paths to 2014/15. Section 5 provides a rapid illustrative review of the system’s performance and productivity, suggesting scope for improvement.

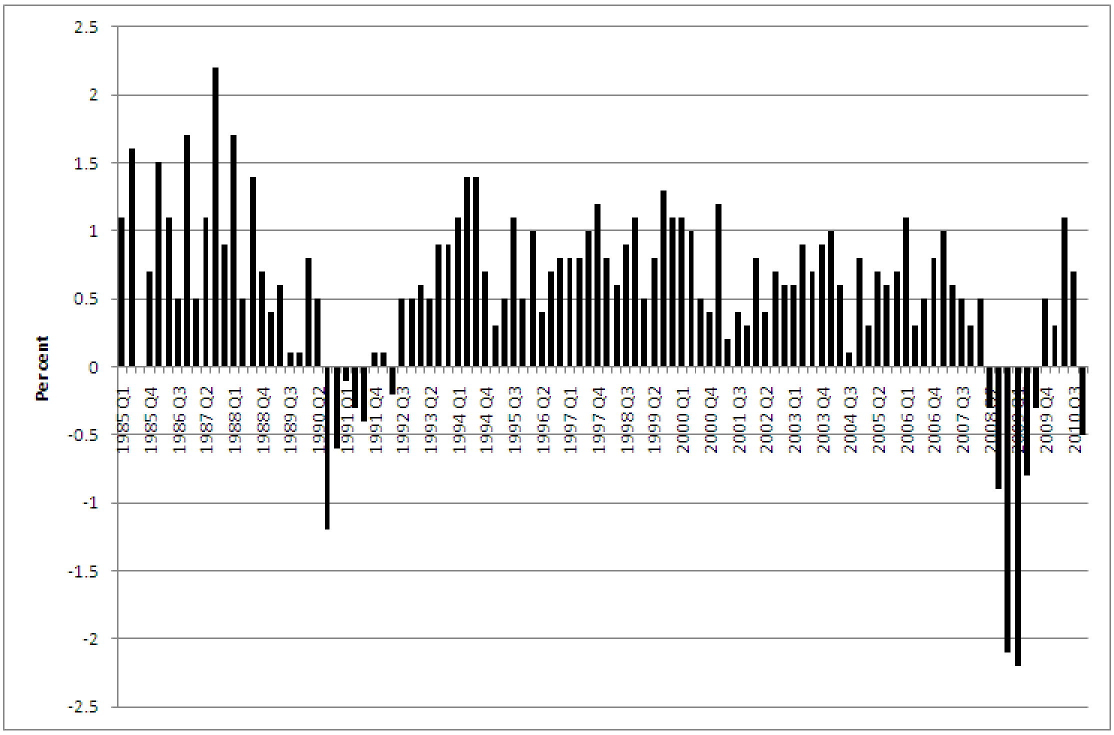
SECTION 2: MACROECONOMIC SITUATION AND PUBLIC FINANCES

The global banking crisis and recession

From the early outward signs of a collapse in the US sub-prime mortgage market in the spring of 2007, the global banking crisis unfolded. Financial institutions thought too big to fail, failed. On September 14th investors in Northern Rock withdrew over £1 billion in the biggest run on a bank in more than a century. In the autumn of 2007 more and more banks start to announce losses. In December the Bank of England cuts a quarter of a percent off interest rates - down to 5.5% - as the scale of the economic impact starts to become clear. This is followed a few months later with a £50 billion plan by the Bank to help banks facing a seizure in credit markets. By 2011, the cost of the financial support to banks and the world economy in general totalled around £7.1 trillion - a fifth of the total annual global economy (Daily Telegraph, 2009). The cost of support by UK government was estimated at around £1.23 trillion - over 80% of its annual GDP. Meanwhile, at just 0.5%, UK central bank interest rates hit their lowest level since 1694.

The economic impact of the crisis was revealed in 2008, when the Office for National Statistics (ONS) publish the second quarter GDP figures. These showed the UK economy had contracted by 0.3%. Five subsequent quarters were also negative and by quarter 3 of 2009 the UK economy had lost around 6% of economic output (see figure 1). This loss is likely to be permanent as, while the UK economy will start to grow, it is unlikely increase at a rate that would take it back to the trend it was on prior to 2007.

Figure 1: UK Gross Domestic Product: Quarter on Quarter growth seasonally adjusted Constant 2006 prices

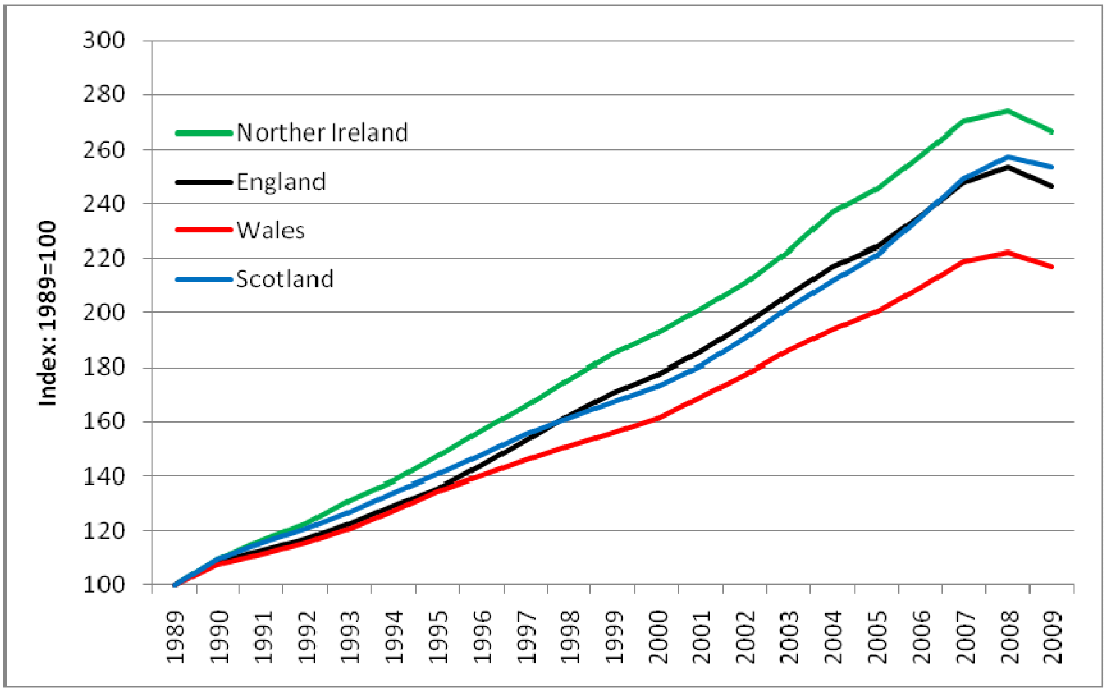


Source: ONS (2011a)

Following modest growth through 2010, the latest provisional GDP figure for the fourth quarter of 2010 suggests the economy once again began to contract - by 0.6%.

The significance of the recession is apparent at regional level too with a reduction in Gross Value Added per capita in 2009 across all four parts of the UK for the first time in two decades (see figure 2).

Figure 2: Gross Value Added per head, smoothed, not seasonally adjusted current prices

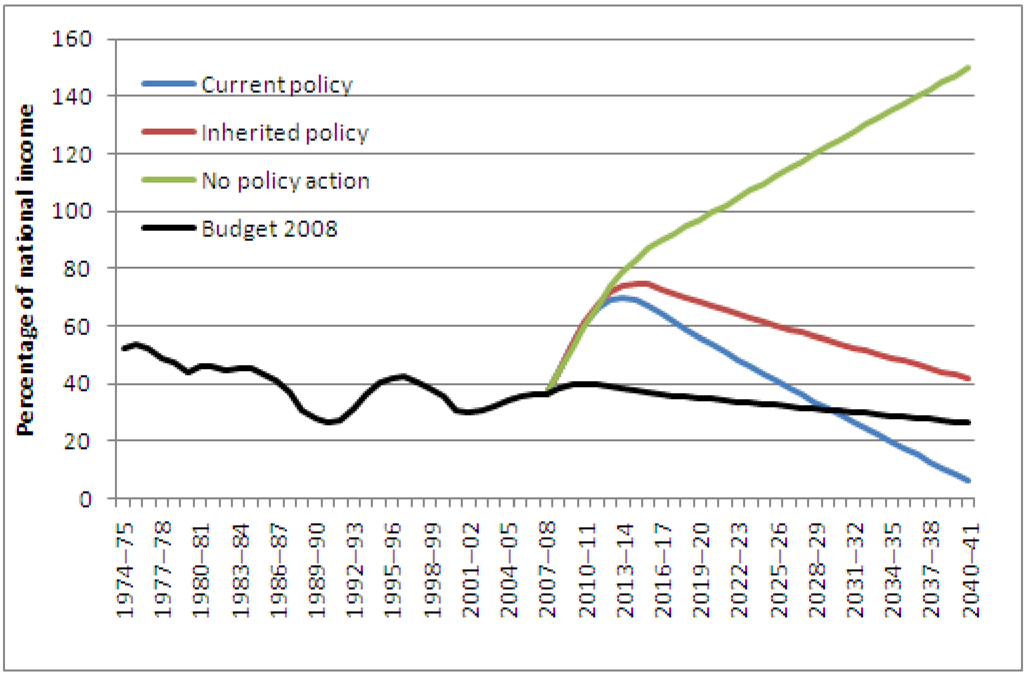


Source: ONS (2011b)

Coalition economic policy

Financing the cost of supporting the banks and the economy as well as the growing gap between revenues and expenditure has meant a growing debt for UK. While economists are not known for their unanimity of opinion, and while there is disagreement over aspects of timing, the balance between tax rises and spending cuts etc, there is near uniform agreement that growing government debt needs to be reduced to sustainable levels. As the Institute for Fiscal Studies (IFS) note in their recent Green Budget (IFS, 2011), the scale of the UK's debt without any policy action is likely to increase to unsustainable levels over the next few years - reaching 100% of GDP by 2019/20 (see figure 3).

Figure 3: Debt forecasts with and without policy action since Budget 2008

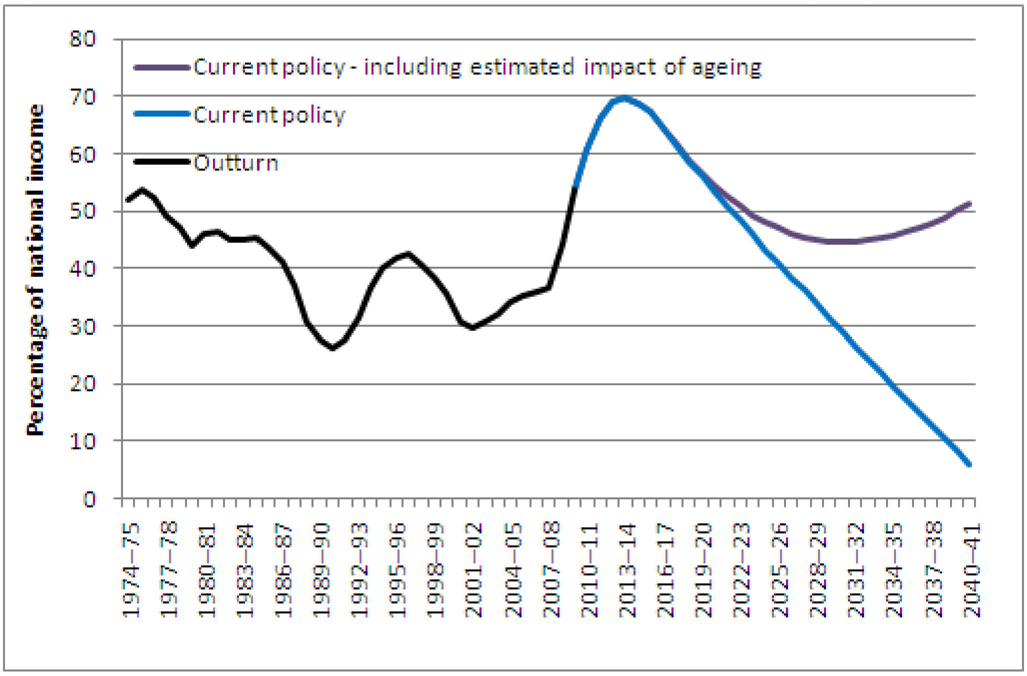


Notes: Forecasts for debt levels assume non-debt interest spending and revenues remain constant as a share of national income form 2017/18 onwards, while inflation is assumed to run at 2.7% a year and real growth in national income at 2.2% a year. Average nominal interest rates are assumed to rise from 4.1% (the level forecast in the 2010 Economic and Fiscal Outlook for the end of the OBR's forecast horizon, 2015/16) to 4.4% between 2017/18 and 2027/28. From 2027/28 onwards, nominal interest rates are assumed to remain at 4.4%. 'No policy action' ignores the direct impact of all fiscal policy measures that have been implemented since Budget 2008. 'Inherited policy' takes policy as of the March 2010 Budget.

Source IFS (2011)

It is also worth noting - as IFS do (see fig 4) - that even with current policies to reduce debt, the impact of demographic change on government spending in the longer term will be a significant issue to tackle.

Figure 4: Debt forecasts with and without the impact of an ageing population



Notes: As for fig 3 above. The forecast including the effects of demographic pressures assumes that the primary balance changes from year to year, beyond 2016/17

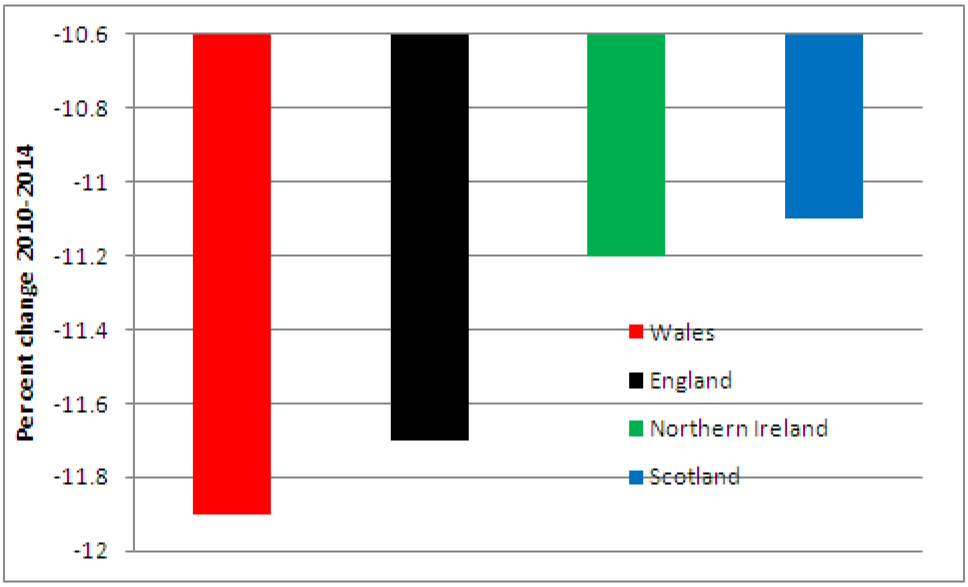
Source: IFS (2011)

Current policy to address the debt issue is essentially a combination of tax increases and cuts in public spending. On the basis of the June Budget and the 2010 spending review, IFS estimate debt will peak at around 70% of GDP in 2013/14 and then fall to the historically sustainable level of around 40% by around 2025/26.

SR 2010 and its impact

The 2010 spending review plans to reduce spending from its peak of 47.4% of GDP in 2009/10 to 39.3% in 2015/16 (HMT, 2010). This will be the most severe five year period for public spending since the Second World War (IFS, 2011). Real terms cuts in departmental expenditure limits (DELs) allocations in all four countries between 2010/11 and 2014/15 range from -11.1% in Scotland to -11.9% in Wales (see fig 5).

Figure 5: Percentage change in Resource + capital DEL: 2010/11 to 2014/15



The pain of these cuts will not be spread evenly however. In particular, in England, for example, health will receive a relative degree of protection (at the expense of other spending areas) with a very small planned real reduction of around 0.2% over the whole of the spending review period (see table 1). If the earmarked transfer of around £1 billion from the NHS budget to social care is excluded, then the English NHS faces a real cut of just over 1.1% by 2014/15. Scotland also plans - for next year at least - to protect its health spending, with a planned real cut of 2.9%. Although less than some other areas, Wales, however, plans a cut of 7.9% by 2013/14. The proposed cut of 2.7% by 2014/15 in the health and social care budget for Northern Ireland also represents a degree of protection relative to other spending areas (see figures 6 and 7).

Table 1: UK regional health budgets (Cash, £ millions)

	2010/11	2011/12	2012/13	2013/14	2014/15	Real change[1]
England						
Health2	103,800	105,900	108,400	111,400	114,400	-0.25%
Social Care[3]	24,600	25,200	25,600	25,700	25,700	-5.45%
Total	128,400	131,100	134,000	137,100	140,100	-1.25%
Northern Ireland						
Health	3,523	3,632	3,758	3,767	3,833	-1.53%
Social Care	900	874	887	906	924	-7.16%
Total[4]	4,424	4,506	4,645	4,673	4,757	-2.70%
Wales						
Health	6,062	6,050	6,032	6,019		-7.72%
Social Care (Central funding only)	109	100	100	99		-15.53%
Total	6,171	6,151	6,132	6,118		-7.86%
Scotland						
Health	11,120	11,063				-2.94%
Social Care	Na	na				
Total	11,120	11,063				-2.94%

Notes:
1. Percentage real change based on HMT GDP deflators (http://www.hm-treasury.gov.uk/data_gdp_index.htm) and 2010/11 vs latest year for which a budget has been set
2. Spending does not include depreciation.
3. PSS for England are estimated figures
4. Excludes Fire service

Sources:
England: HMT (2010)
Northern Ireland: Northern Ireland Executive (2011)
Wales: Welsh Assembly (2011)
Scotland: The Scottish Government (2010)

Figure 6: 7th March NI Budget: Percentage real changes 2010-2014/15 by spending area

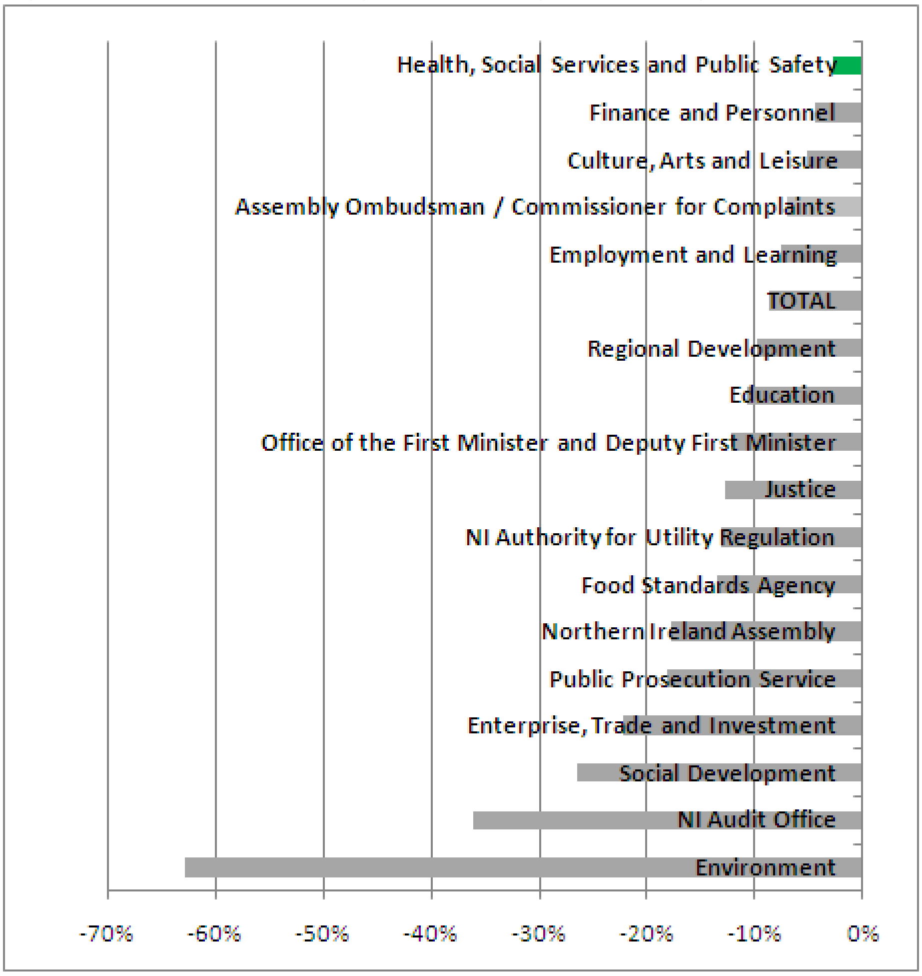
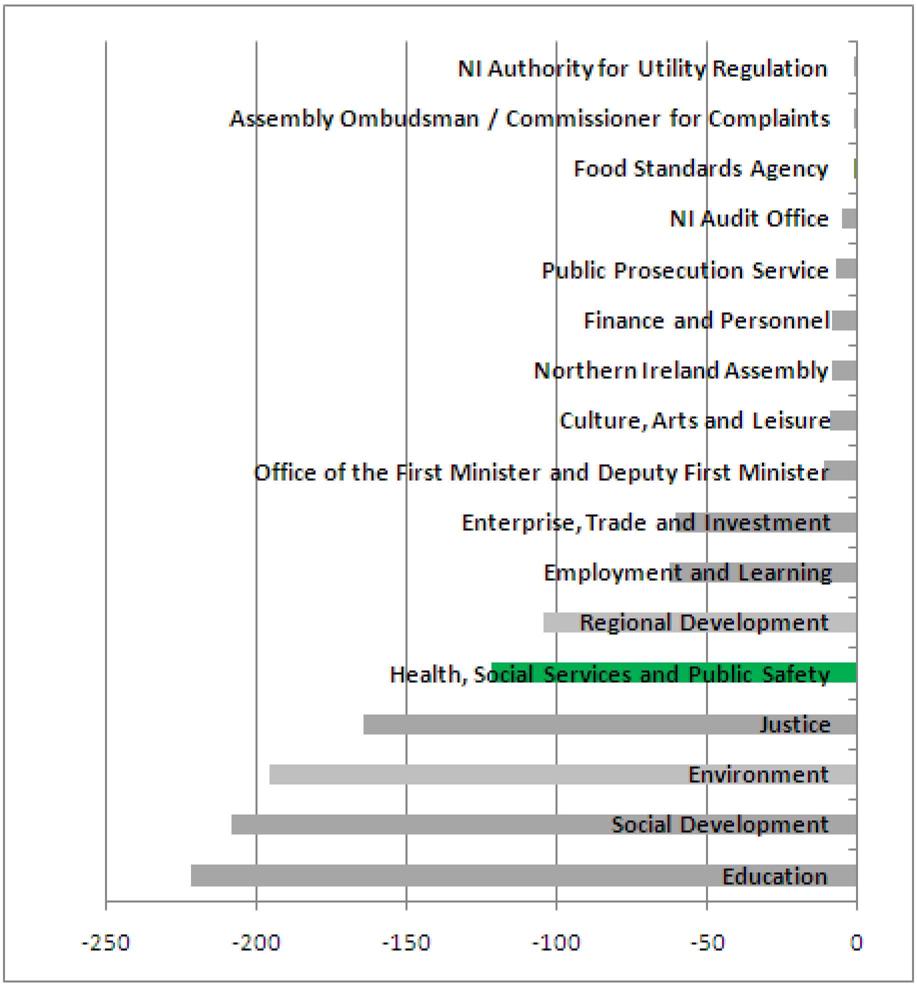


Figure 7: 7th March NI Budget: Real changes (£m) 2010-2014/15 by spending area

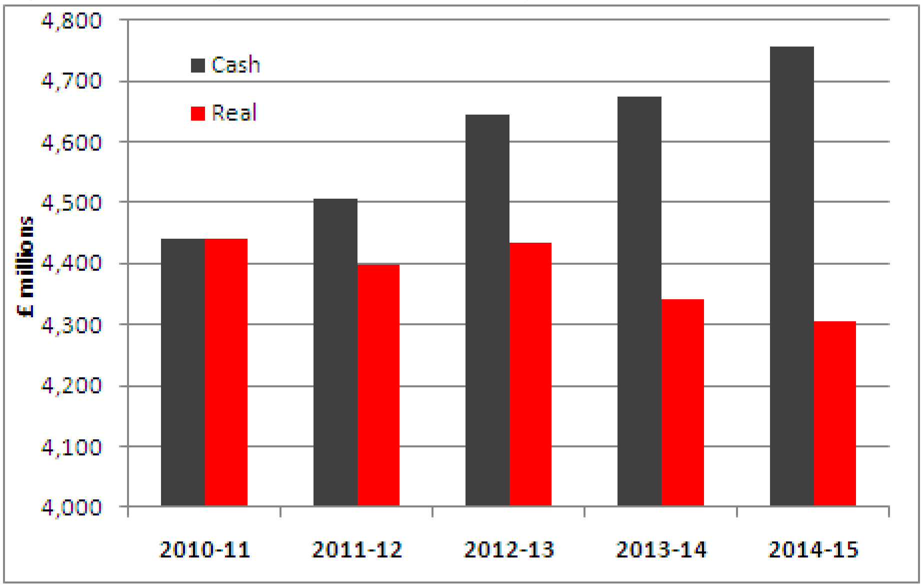


The impact of the spending review and decisions at regional level on social care spending are less clear. In Wales, the expectation is that for 2011/12, social services funds made available from the Health and Social Services Group (which do not cover all spend) will be cut by 8% in cash terms (although much of this apparent cut appears to be a transfer to another budget outside of the group). In England, while overall real cuts to local authority budgets will amount to around 27% by 2014/15, this will not necessarily translate to an equivalent cut in social services budgets as this will depend on priority decisions by individual councils. However, one expectation is a real cut of between 7% and 14% nationally. No decisions are yet known for Scotland.

While the Northern Ireland draft budget proposes a cumulative real cut of 2.7% by 2014/15, as figure 8 shows, changes from year to year vary.

It is important to note that these real changes in proposed budgets (and all real figures in this section) are calculated on the basis of a general measure of economy-wide inflation, the GDP deflator. Predictions for this measure of inflation are made by HMT (and the Office for Budget Responsibility). For various reasons - the public sector pay freeze from 2011 to 2013, the fact that NHS non-pay inflation tends to be lower than the GDP deflator (used as a proxy in forecasting non-pay inflation[1]) - the real change in the health and social care budget shown in figure 8 is probably an over estimate; by 2014/15 the real cut - based on inflation specific to the health and social care services - could be nearer 2% than 2.7% - an average of around 0.5% per year rather than 0.7%.

Figure 8: NI Budget: Cash and real change (£m): Health and Social Care



Summary

- The global financial crisis and ensuing recession have left national finances in considerable imbalance. Correcting an unsustainable debt and deficit position has entailed increases in taxation and severe cuts in public spending.

- BY 2014/15, the 2010 spending review plans cuts in departmental spending of around 11% in real terms (in addition to cuts in welfare benefits).

- Spending cuts have not been spread evenly, with health care in all four territories of the UK being ‘protected’ to varying degrees relative to other spending areas.

- Spending changes for personal social services over the next four years across the UK are less certain, due to local spending decisions by councils in, for example, England.

- The latest Budget for Northern Ireland suggest health and social care will receive a real cut in its budget by 2014/15 of around 2.7%. This compares to a real cut of

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[1] Between 1999/2000 and 2009/10, the GDP deflator rose by 44% (2.1% per year) while non-pay inflation in the NHS in England rose by 14% (0.78% per year).

around0.25% (more if social care is included) in England, a real cut of around 7.9% in Wales (by 2013/14) and, for next year at least, a real cut of 2.9% in Scotland (not including social care).

- All health and social care services across the UK thus face one of the most severe funding situations since the Second World War.

SECTION 3: COMPARATIVE HEALTH AND SOCIAL CARE NEEDS

Re-estimates of Northern Ireland’s relative health and social care needs

The approach taken by the 2005 review (Appleby, 2005) to estimate future spending paths for health and social care in Northern Ireland was to try and establish Northern Ireland’s ‘fair share’ of the increase in future spending for the UK as recommended by Derek Wanless’s 2002 report (Wanless, 2002). The 2005 review looked at eight models to estimate Northern Ireland’s health and social care needs relative to those of England and then applied these relative needs weights to the additional funding recommended by Derek Wanless.

This current review has updated three of these needs models - the Treasury’s basic Needs Assessment Study (NAS) model (as further updated in 2001 as part of the Northern Ireland Executive’s Needs and Effectiveness Evaluation study), the Northern Ireland health and social care allocation model and the English weighted capitation model - the latter two are used to distribute annual budgets across health and social care areas (in the case of Northern Ireland) and NHS primary care trusts (in the case of England). The results of using more recent data and, in the case of the allocation models, more up to date models following various changes over the last few years are summarised in table 2.

Table 2: Summary of Northern Ireland’s health and social care needs relative to England

	2005 Review	**2011 update**		
		DLA not reduced	**DLA reduced[1]**	**DLA NI=predicted**
	%	**%**	**%**	**%**
HMT NAS				
Basic model	**4.0**	**6.0**		
NI Executive update	**13.2**			
NI Executive+ update	**16.5**			
EQ-5D	**4.0**			
NI Allocation model				
Acute (elective)	4.1	4.0		
Acute (Non-elective)		7.2		
Maternity	12.1	8.9		
Family	18.5	15.2		
Elderly	-13.3	-3.4		
Mental Health	42.6	43.6		
Learning Disability	58.9	59.1		
Physical Disability	71.1	75.6		
Health promotion	6.4	9.4		
Adult community care	5.2	8.4		
General Medical Services	15.2	16.2		

Prescribing	1.7%	-5.8		
Total	**9.5**	**11.5**		
Total (inc. rurality and cost factors)	**11.6**			
English Allocation model				
HCHS	**13.3**	10.7	10.3	8.9
Prescribing		11.6	10.3	5.3
Primary medical services		10.8	10.8	10.8
Health Inequalities		47.1	47.1	47.1
NHS total		10.8	10.4	8.7
Personal Social Services[2]	**13.3**	41.7	38.7	30.2
NHS+PSS[3]	**13.3**	**17.2**	**16.3**	**13.2**

Notes

1. The English allocation model was run using actual Disability Living Allowance claimant rates as well as a *reduced* rate based on the English rate plus 5/6ths of the difference between the actual English and Northern Ireland claim rates. The final column shows the impact of assuming DLA rates in Northern Ireland were in line with the relationship between DLA claims as a percentage of working age population and rates of limiting longstanding illness (ie, 36% less than actual DLA rates)[2]
2. PSS relative need assumed equal to HCHS
3. The updated relative needs figures include adjustments for the Market Forces Factor (MFF) and an emergency ambulance cost adjustment (EACA).

Further details of the work carried out by DHSSPS staff on these updated models is contained in Appendix 1.

Uncertainties and sensitivities

HMT NAS model

The HM Treasury NAS model was developed in the 1970s with updates in 1994. While used to inform funding decisions it was not used to allocate resources across the UK (instead, the Barnett formula was employed to do this). As the 2005 review pointed out, since being updated in 1994, there has been extensive econometric work on health care funding allocation formulae which suggest the HMT NAS remains a relatively crude model for determining relative need. However, it is included here for comparative purposes. Using more up to date data suggests that Northern Ireland's relative needs are around **6%** higher than England - 2% more than the estimate produced by the 2005 review.

Northern Ireland allocation model

Populating the Northern Ireland health and social care model with English data (in essence treating NI and England as two regions in order to allocate a combined budget) suggested that, in the 2005 review, health and social care needs in Northern Ireland were around 9.5%

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[2] There is a strong positive relationship between rates of DLA for working age population and proportions of that population stating they have a limiting long standing illness across regions of the UK (see figure 9). Northern Ireland however has DLA claimant rates which are significantly higher than its LLI rates would suggest.

higher than in England implying **9.5%** higher per capita spend in Northern Ireland. The equivalent up dated figure is now around **11.5%.** The 2005 review also estimated the extra costs associated with a greater level of sparsity plus some additional costs, to produce an increased level of need of 11.6%. The current review has not made these further adjustments.

As with the 2005 review, these results are very sensitive to certain parameters in the model. For example, while learning disabilities and physical and sensory disabilities programmes of care account for just 8.8% of total spend, on the basis of the model, their relative needs are such that they account for around 50% of Northern Ireland's *total* relative need; setting the relative needs indices for these two programmes of care to one (ie no difference with England) reduces overall relative needs from 11.5% to 5.9%.

Moreover, while mental health needs in Northern Ireland are estimated to require nearly 44% higher per capita funding than in England, actual spending (for a programme that consumes just 7% of total spend) is somewhat lower - possibly between 10% and 30%[3] lower than per capita spending on mental health in England. If this lower spending is a better reflection of actual need, then reducing the mental health relative need measure to reflect lower per capita spending implies an overall relative need of between 6.2% and 7.6% - for a programme that currently consumes around 7% of the total budget. It is worth noting that spending on mental health between 2007/8 and 2009/10 has increased by around 9% in real terms.

These examples of the sensitivities of the allocation model are not meant to imply that the weightings for mental health or physical and learning disabilities are necessarily wrong, but rather to illustrate that small changes in one or two elements of the model can lead to significant changes in the overall relative needs weighting.

English NHS weighted capitation and social care relative needs formula model

A similar exercise - but populating the then English NHS a weighted capitation model with Northern Ireland data - suggested in the 2005 review that Northern Ireland had higher needs, equivalent to an additional **13.3%** per capita spend. As can be seen from table 2 however, the model used in 2005 only included spending on hospital and community health services (around 77% of total health spend) and did not make any estimates for relative need for other elements of the health budget. The model also assumed that personal social services relative need would be the same as that for HCHS.

Since then, the English capitation formula has been revamped following a review in 2007 (Morris et al, 2007)). The new formula (applied in 2009/10 and 2010/11 to set target allocations for PCTs) includes various structural changes including a new element to cover variations between PCTs in life expectancy: an attempt to build in an element in the allocation for health inequalities.

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[3] The 10% figure was estimated by Professor David Bamford's 2007 review of mental health and learning disability (Bamford, 2007). The estimate of 30% lower per capita spend has been estimated by DHSSPS for the purposes of this review. It remains a broad estimate.

Using this new formula and, where possible, new data, the closest equivalent needs figure to the 2005 review is that for HCHS. This suggests a reduction in relative needs to **10.7%** for this spending area. For health (the NHS) overall, the relative need is **10.8%,** for social care, **41.7%** and for the NHS and social care combined, **17.2%.**

However, as with the previous model, these estimates are sensitive to a small number of factors. For example, Disability Living Allowance (DLA) claimant rates feature as a variable in the English NHS allocation formula and the personal social service relative need index. However, as was noted in the 2005 review (Appleby, 2005), while the 18-64 NI DLA recipient rate is around 133% higher than in England, rates of longstanding illness are only 14% higher. Research has suggested that around two thirds of the difference can be explained by health factors - a combination of LLI, mortality and hospital admission rates (Rosato and O' Reilly, 2006). DHSSPS analysis suggests that, '..*allowing mental health status and hidden unemployment to explain half the remaining difference[between NI and England], a reasonable compromise might be that 5/6th of the differential [to be] applied to the [English allocation] formula.*' The results of this reduced level of DLA are shown in column 4 of table 2. Overall, the relative need measure is reduced from 17.2% to 16.3%.

An alternative reduced DLA has been used to derive needs estimates in the final column of table 2. Across the regions of the UK (excluding Northern Ireland) there is, as figure 9 shows, a strong positive relationship between the proportion of the working age population in receipt of DLA and the proportion reporting limiting longstanding illness (from the 2001 Census) - except for Northern Ireland, which appears to have a much higher DLA rate than its level of LLI would suggest[4]. Reducing Northern Ireland's DLA claimant rate to the level suggested by its LLI (based on the relationship between DLA and LLI for all regions excluding Northern Ireland) and using this reduced rate in the English allocation formula reduces the overall relative need figure by 5 percentage points from 17.2% to 13.2%.

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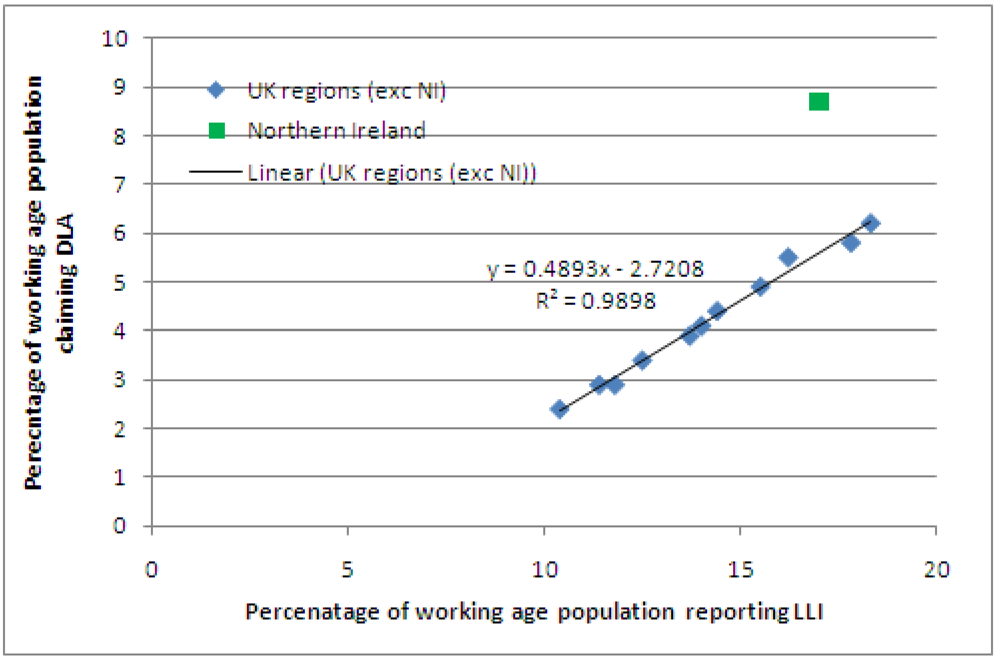
[4] Data from The Poverty Site (2011):

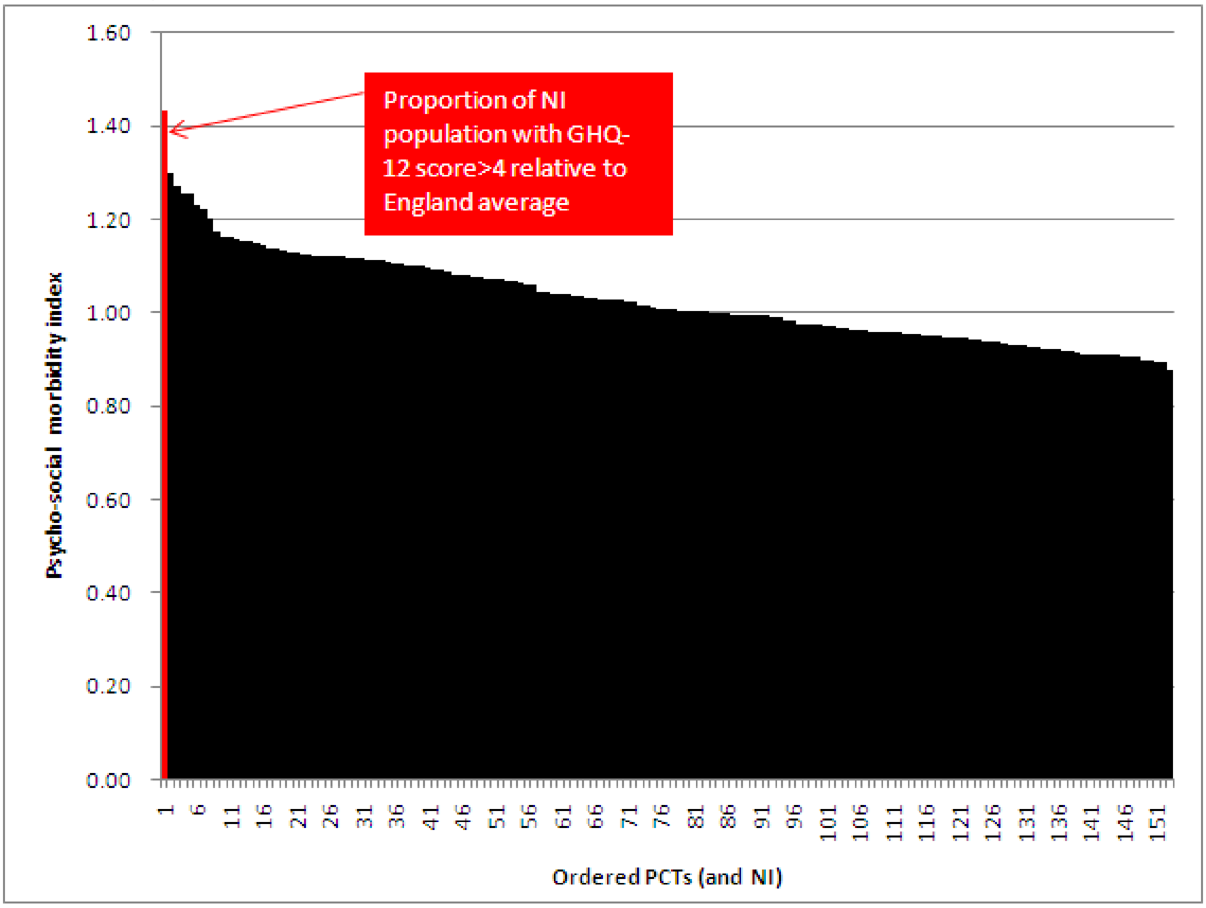
Figure 9: Relationship between DLA claimant rates and rates of Limiting Longstanding Illness (LLI)



Source: Data, The Poverty Site (2011)

Further, as with the Northern Ireland model, the final relative needs measure derived from the English allocation model is sensitive to the relative needs measures of individual spending areas. For example, setting the relative needs measure for mental health equal to England reduces the overall relative need from 17.2% to 12.8% even though mental health spend is just 7% of the NI health and social care budget - significantly less than implied by the high relative need for this spending area. Further, overall estimates of relative need can be sensitive to individual factors within just one spending area. For example, the psycho-social morbidity measure - one of four variables used to construct the mental health needs index - is measured to be around 43% higher than the English average, in fact, significantly higher than any English PCT (see figure 10). If this is set equal to the English average, the overall relative needs for health drops from 10.8% to 7.8% and for the health and social care combined, from 17.2% to 14.9%.

Figure 10: Distribution of the psycho-social morbidity index: English PCTs and Northern Ireland (England=1)



Again, as with the examples of the sensitivities of the Northern Ireland allocation model to changes in just one or two components of the formula, these examples are not meant to imply that elements of the English allocation model (when populated with Northern Ireland data) are necessarily wrong or need changing. However, it is important to be aware of of the sensitivities of these allocation models. As the history of their development over the last thirty years or more shows, as evidence has accumulated and more sophisticated statistical techniques have been applied to the difficult issue of assessing relative need, the structure of such models has changed, as have the weights and combinations of needs indicators.

What level of relative need?

As the 2005 review concluded, there are reasons to favour the English capitation model as it has a relatively stronger evidence base for the weights it employs and that in a UK-wide analysis to determine needs weights, English data would dominate. However, again as the 2005 review noted, there are uncertainties and sensitivities in the model which can significantly alter the final overall relative needs figure. Based on updating the new English capitation formula more and with more comprehensive coverage of the elements of the formula, the relative needs for NI fall from 13.3% (in the 2005 review) to 10.8%. It is the inclusion of the relative needs formula for personal social services that brings the combined needs weight to 17.2%. However, the PSS element is very sensitive to just one variable in the English formula - the level of DLA claimants. Reducing the relatively high Northern Ireland DLA rate to that predicted by NI's level of limiting longstanding illness (as reported in the 2001 Census), reduces the PSS needs weight from 41.7% to30.2% and the overall weight to 13.2%. If this change and others (for example, those related to sensitivities concerning the psycho-social morbidity index) are combined, the overall needs weight falls even further.

All things considered, therefore, the judgement of this current review is that an additional needs factor of +9% might be considered a reasonable needs differential between England and Northern Ireland. It needs to be stressed that this is a judgement that tries to take account of the variation in results between the models examined and the sensitivities inherent in the results for each model.

As will be seen next, when applying the additional needs factor to 2002 Wanless funding recommendations (as applied to Northern Ireland) the actual choice of level of additional need in fact has a much smaller impact on the final funding figure for 2014/15 than the Wanless spending recommendations; every 1% additional needs only adds between £11 million and £15 million (depending on the Wanless scenario) to the final 2014/15 spending level.

Future Northern Ireland funding needs

Table 3 presents estimates of Northern Ireland health and social care funding needs from 2007/8 (the base year) to 2014/15. These estimates are based on applying the increases in funding for UK health care spending recommended by the 2002 Wanless review to Northern Ireland using the methodology of the 2005 Appleby review.

Northern Ireland's share of the Wanless funding growth for each of the three Wanless scenarios (Solid Progress, Slow Uptake and Fully Engaged) have been based, as in the 2005 review, on the Barnett share for Northern Ireland and not on the total spend in the base year and then the same growth as England thereafter.

Five separate funding paths are shown; three based on updated relative needs models (HMT NAS, Northern Ireland capitation and English capitation) together with the 2005 review's judgement of a 7% additional need relative to England and this current review's judgement of a 9% additional need. As can be seen from the table, the variation in growth in funding (at 2010/11 prices) from 2010/11 to 2014/15 for the different models is relatively small compared to the increase resulting from applying the Wanless recommendations. For example, for the Solid progress scenario, the funding increase by 2014/15 across all five projections ranges from £969 million to £1,101 million.

Using 2007/8 as a base year increases the estimate of the growth in funding needed between 2010/11 and 2014/15 by between £270 million and £430 million (based on 9% additional needs) compared with using 2010/11 as a base year (with the implicit assumption that funding between 20017/8 and 20010/11 matched that recommended by Wanless). Column 10 in table 2 shows what the increase between 2010/11 and 2014/15 based on

2010/11 base year would be. Columns 11-13 reproduce columns 8 to 10 but in nominal or cash terms (ie without any adjustment for inflation).

Table 3: Northern Ireland health and social care funding needs: 2007/8-2014/15

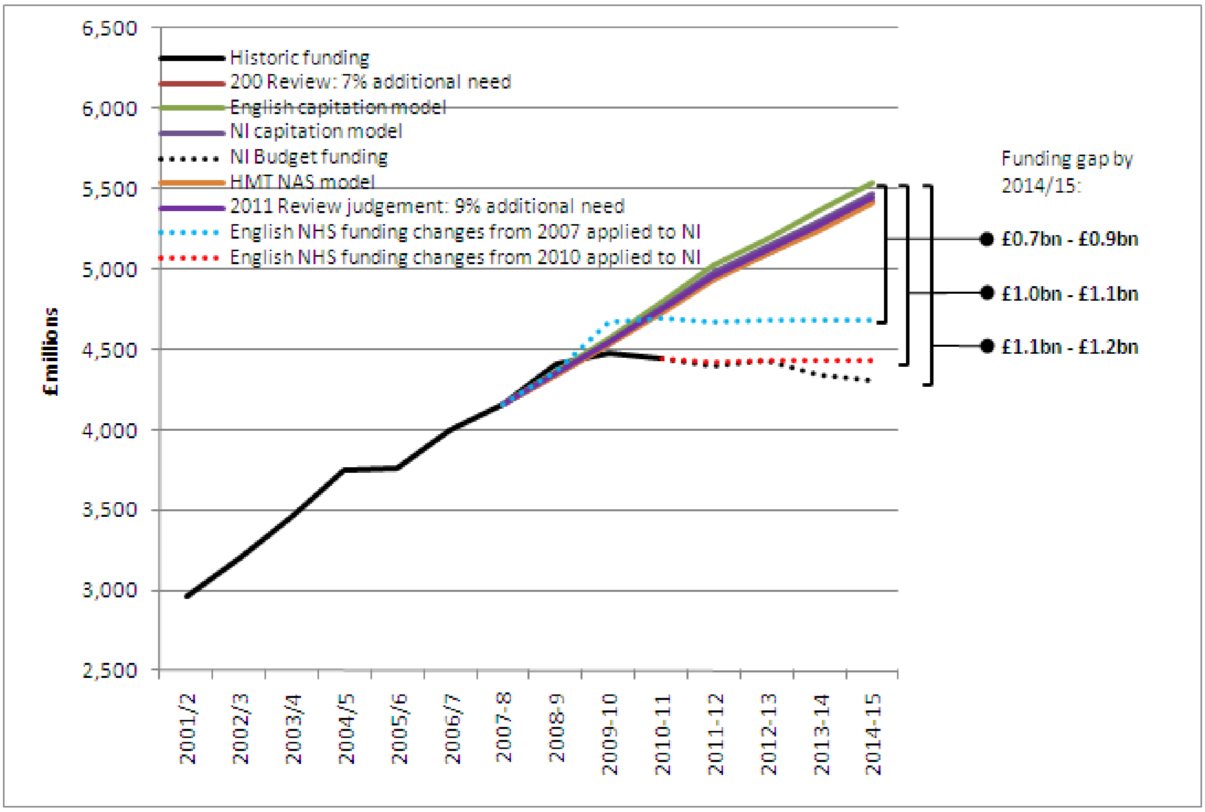
									2010/11-2014/15 Relative to actual 2010/11 spend (£4,441bn)	2010/11-2014/15 Assuming spending matched Wanless recommendations between 2007/8 and 2010/11	2014-15	2010/11-2014/15 Relative to actual 2010/11 spend (£4,441bn)	2010/11-2014/15 Assuming spending matched Wanless recommendations between 2007/8 and 2010/11
									2010/11 prices	2010/11 prices	Current prices	Current prices	Current prices
	2007-8 Col1	2008-9 Col2	2009-10 Col3	2010-11 Col4	2011-12 Col5	2012-13 Col6	2013-14 Col7	2014-15 Col8	Col9 (col8-4,441)	Col10 (col8-col4)	Col11 (col8*1.1049)	Col12 (col11-4,441)	Col13 (col11-col4)
HMT NAS model +6.02%													
Solid Progress	4159	4,341	4,532	4,731	4,939	5,088	5,246	5,410	969	679	5,977	1,536	1,246
Slow Uptake	4159	4,379	4,611	4,855	5,112	5,312	5,525	5,745	1,304	890	6,348	1,907	1,493
Fully Engaged	4159	4,332	4,513	4,701	4,897	5,034	5,179	5,327	886	626	5,886	1,445	1,185
NI Capitation model +11.5%													
Solid Progress	4159	4,351	4,551	4,760	4,979	5,136	5,303	5,474	1,033	714	6,049	1,608	1,288
Slow Uptake	4159	4,391	4,634	4,891	5,162	5,372	5,595	5,827	1,386	936	6,439	1,998	1,547
Fully Engaged	4159	4,341	4,531	4,729	4,935	5,079	5,231	5,388	947	659	5,953	1,512	1,224
England Capitation Model 17.2%													
Solid Progress	4159	4,360	4,571	4,791	5,021	5,186	5,361	5,542	1,101	751	6,123	1,682	1,332
Slow Uptake	4159	4,402	4,659	4,929	5,213	5,434	5,669	5,913	1,472	984	6,533	2,092	1,604
Fully Engaged	4159	4,351	4,550	4,758	4,975	5,126	5,286	5,451	1,010	692	6,022	1,581	1,264
2005 Review judgement +7%													
Solid Progress	4159	4,343	4,535	4,736	4,946	5,096	5,256	5,421	980	685	5,990	1,549	1,254
Slow Uptake	4159	4,381	4,615	4,862	5,121	5,323	5,537	5,760	1,319	898	6,364	1,923	1,503
Fully Engaged	4159	4,334	4,516	4,706	4,904	5,042	5,188	5,338	897	632	5,898	1,457	1,192
2011 Review judgement +9%													
Solid Progress	4159	4,346	4,542	4,747	4,960	5,114	5,277	5,445	1,004	698	6,016	1,575	1,269
Slow Uptake	4159	4,385	4,624	4,875	5,139	5,345	5,563	5,790	1,349	915	6,397	1,956	1,523
Fully Engaged	4159	4,337	4,523	4,716	4,918	5,058	5,207	5,360	919	644	5,923	1,482	1,206

Future funding gaps

Given these estimates of funding needs, how do they compare with actual and planned funding since 2007/8?

Figure 11 takes one Wanless scenario - Solid Progress - and funding estimates based on the five alternative additional funding needs models/judgements and sets these against three different funding scenarios: the Northern IrelandBudget, a notional Northern Ireland spend to 2014/15 assuming the same planned changes as for the English NHS budget from 2010/11 arising from the 2010 spending review, and a similar notional spend/budget but starting from 2007/8.

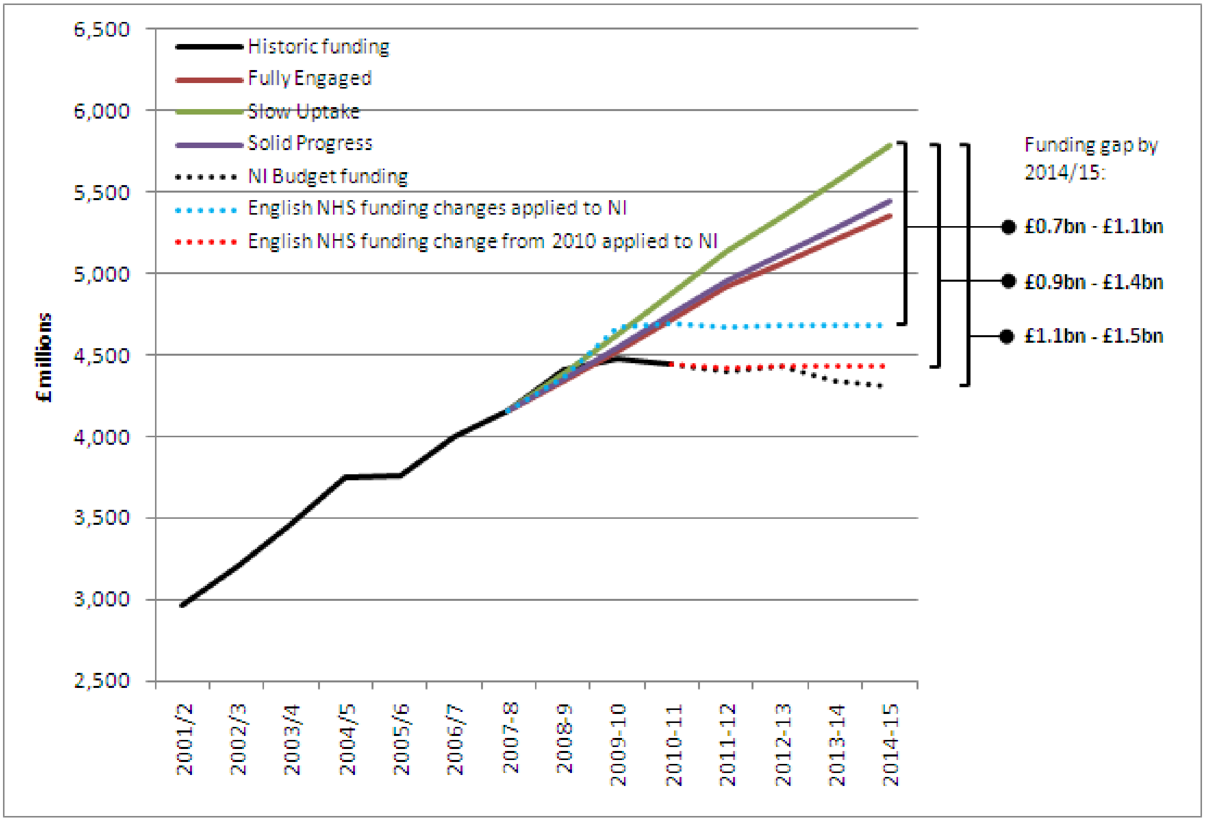
Figure 11: Funding gap based on Solid Progress scenario for four relative needs estimates: 2010/11 prices



While Northern Ireland spending kept pace with needed funding between 2007/8 and 2009/10, a gap opened up in 2010/11 (of between £290 million to £350 million depending on the relative needs model for the Solid progress scenario). From 2011/12 to 2014/15 this gap continues to widen so that by 2014/15 the difference between the NI Budget and funding needs estimates reaches up to £1.2 billion.

Figure 12 presents a similar analysis of the funding gap but based on this review's judgement of a relative need of +9%. Here the funding gap varies between £1.1 billion and £1.5 billion depending on the three Wanless scenarios.

Figure 12: Funding gap based on 9% additional need: 2010/11 prices



Summary

- The judgement of this review is a needs differential for Northern Ireland relative to England of +9%

- The difference in additional funding due to the choice of additional need for Northern Ireland relative to England is relatively small; every 1% additional need translates into £11 million to £15 million additional funding by 2014/15 as the additional needs factor is applied to the marginal growth in funding not the entire Northern Ireland spend.

- Using 2007/8 as a base year, updating three relative needs models used by the 2005 Appleby review and applying Wanless 2002 future funding recommendations to Northern Ireland suggests funding of between £5,327 million and £5,913 million by 2014/15 (at 2010 prices, or £5,886 million and £6,533 in cash terms) depending on the relative additional needs and Wanless scenario across all three models

- Using 2010/11 as a base year, funding requirements in 2014/15 would be £5,067 million and £5,377 million in real terms (£5,608 million and £5,941 million in cash terms) depending on the relative additional needs and Wanless scenario across all three models.

- On the basis of additional needs of +9%, required funding by 2014/15 is projected to be between £5,360 million and £5,790 million (£5,923 and £6,397 million in cash terms) depending on the Wanless scenario adopted.

- Compared with the latest Budget proposals for Northern Ireland, the gap with funding suggested by Wanless and a +9% needs differential will amount to between £1.1 billion and £1.5 billion depending on the Wanless scenario.

- If, however, Northern Ireland had received the same funding increases as the English NHS from 2007/8 to 2010/11 (and the equivalent SR 2010 settlement as the NHS to 2014/15) then the funding gap would be between £0.7 billion and £1.1 billion.

SECTION 4: THE NORTHERN IRELAND PRODUCTIVITY CHALLENGE

Estimates of the productivity challenge

An often overlooked but crucial element of Sir Derek Wanless's 2002 review of the future funding needs of health care in the UK was assumptions he made about future NHS productivity. Over the period 2010/11 to 2014/15, these amounted to productivity increases of around 2% to 3% per annum. Without this growth in productivity, real funding growth between 2007 and 2015 of around 32% as recommended by Wanless would have needed to be over 57%.

In considering the funding gaps (identified in the previous section) from the point of view of the productivity gains needed to close the gap (in the absence of funding) account needs to be taken of the assumptions Wanless made about productivity.

The productivity challenge

Table 4 reworks the funding gap analysis above incorporating Wanless' assumptions about NHS annual productivity gains (from 2007/8) in relation to the proposed DFP Draft Budget for the years 2011/12 and, historically, actual funding from 2007/8 to 2010/11.

As can be seen the productivity gap (as opposed to the Wanless funding gap) increases for all models and scenarios. In terms of the favoured additional needs scenario for this review, by 2014/15 the productivity gap ranges from £2 billion to £2.2 billion (at 2010/11 prices). This represents an increase of around 54% to 57% of the actual spend in 2007/8. It needs to be noted that these figures include recovering from the historic gap in funding that started in 2009/10.

Table 4: Productivity improvement challenge

		2008-9	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2007/2015
HMT NAS +6.02%									
Solid Progress	%	0.0%	5.1%	7.4%	7.6%	4.3%	7.8%	6.6%	54.0%
Slow Uptake	%	0.5%	5.1%	7.4%	7.6%	4.6%	7.6%	6.4%	54.7%
Fully Engaged	%	-0.3%	4.9%	7.1%	7.3%	4.1%	7.5%	6.3%	51.6%
Solid Progress	£m	-2	224	346	380	232	436	392	2,008
Slow Uptake	£m	19	228	350	384	246	429	382	2,039
Fully Engaged	£m	-11	214	334	366	217	418	372	1,909
NI Capitation +11.5%									
Solid Progress	%	0.3%	5.4%	7.7%	7.9%	4.5%	8.0%	6.8%	56.6%
Slow Uptake	%	0.8%	5.5%	7.7%	7.9%	4.8%	7.8%	6.6%	57.3%
Fully Engaged	%	0.0%	5.2%	7.4%	7.6%	4.3%	7.7%	6.5%	54.2%
Solid Progress	£m	11	239	362	397	245	455	411	2,120
Slow Uptake	£m	33	243	367	402	261	447	400	2,152
Fully Engaged	£m	2	228	349	382	230	435	389	2,016
England Capitation +17.2%									
Solid Progress	%	0.6%	5.7%	8.0%	8.1%	4.8%	8.2%	7.0%	59.3%
Slow Uptake	%	1.2%	5.8%	8.0%	8.2%	5.0%	8.0%	6.8%	60.1%
Fully Engaged	%	0.4%	5.5%	7.7%	7.9%	4.5%	7.9%	6.7%	56.8%
Solid Progress	£m	25	254	379	415	260	474	430	2,236
Slow Uptake	£m	48	259	384	420	276	465	419	2,270
Fully Engaged	£m	15	243	365	400	244	453	407	2,127
2005 Review judgement +7%									
Solid Progress	%	0.0%	5.1%	7.4%	7.6%	4.4%	7.8%	6.6%	54.4%
Slow Uptake	%	0.5%	5.2%	7.5%	7.7%	4.6%	7.6%	6.4%	55.2%
Fully Engaged	%	-0.2%	4.9%	7.2%	7.4%	4.1%	7.6%	6.4%	52.1%
Solid Progress	£m	1	227	349	383	234	440	395	2,028
Slow Uptake	£m	22	231	353	387	249	432	386	2,059
Fully Engaged	£m	-9	217	337	369	220	421	375	1,929
2011 Review judgement 9%									
Solid Progress	%	0.1%	5.3%	7.5%	7.7%	4.5%	7.9%	6.7%	55.4%
Slow Uptake	%	0.6%	5.3%	7.6%	7.8%	4.7%	7.7%	6.5%	56.1%
Fully Engaged	%	-0.1%	5.0%	7.3%	7.5%	4.2%	7.6%	6.5%	53.0%
Solid Progress	£m	5	232	355	389	239	446	402	2,069
Slow Uptake	£m	27	236	359	394	254	439	392	2,100
Fully Engaged	£m	-4	222	342	375	224	427	381	1,967

Figures 13 and 14 summarise the productivity gap graphically for the various models under the Solid Progress scenario and specifically for the +9% additional need judgement for all Wanless scenarios.

Figure 13: Productivity challenge: Alternative needs additions, Solid Progress plus Wanless productivity assumptions

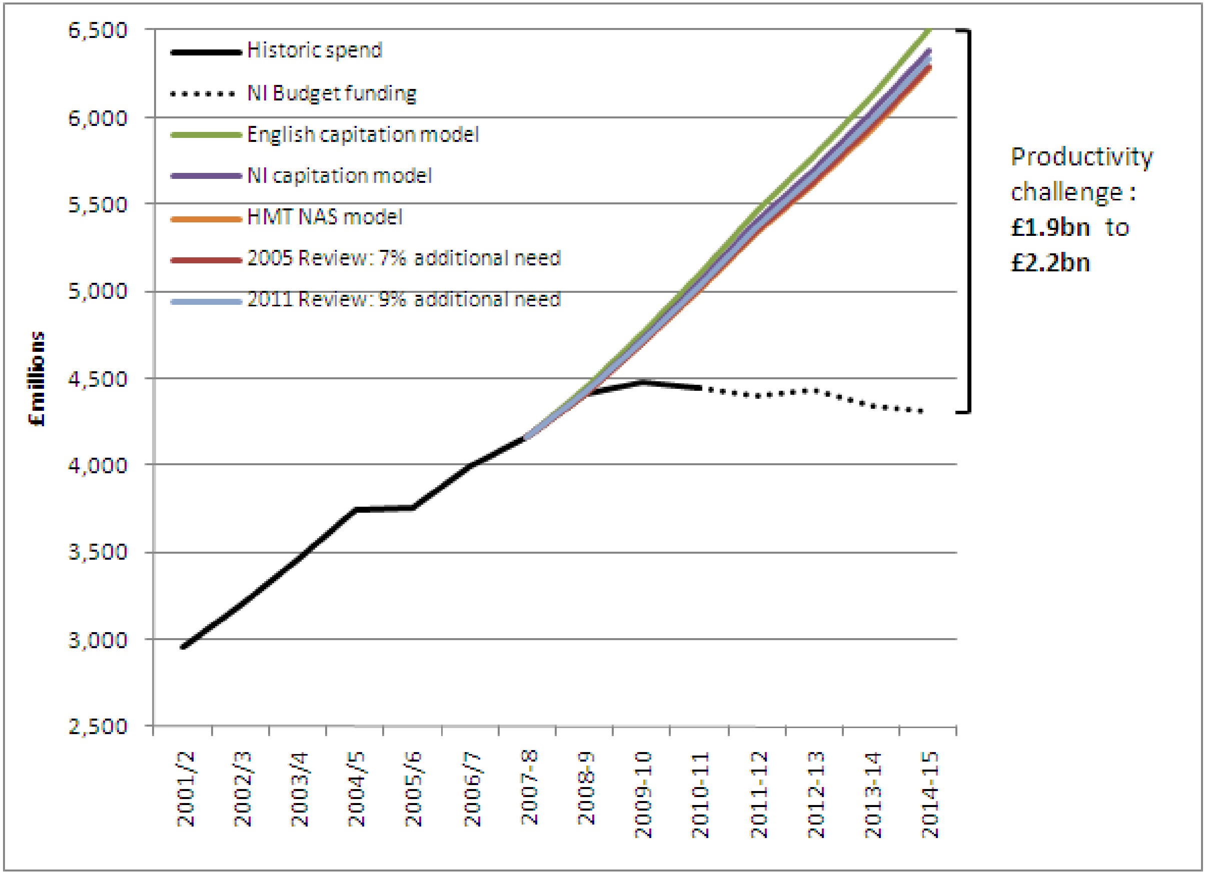
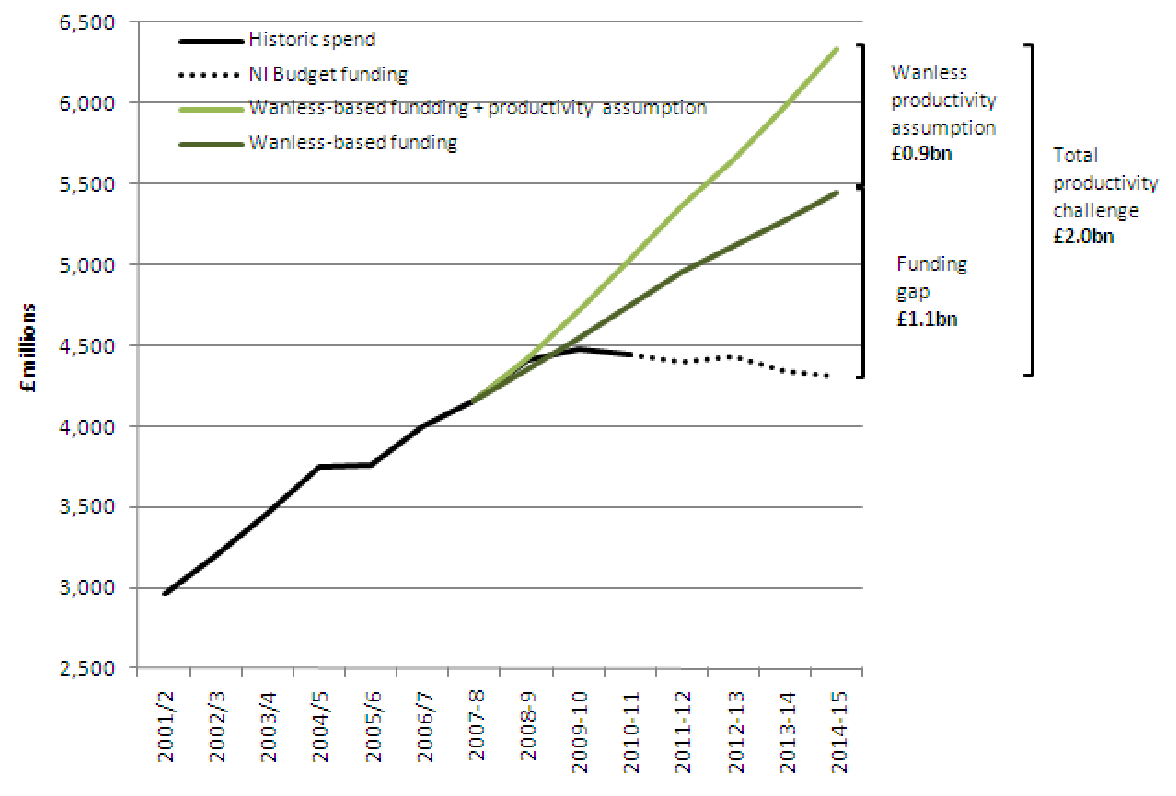


Figure 14: Productivity challenge: 9% additional needs, Solid Progress plus Wanless productivity assumptions



Compared with the Northern Ireland Budget plan for 2014/15 of £4,306 million (at 2010/11 prices), for the +9% relative additional need judgement the Wanless-based funding need plus Wanless productivity assumptions amount to £6,336 million (and hence a gap of around £2 billion). Closing this gap would require a productivity increase of around 30% over the next four years, or around 6.8% each year. This represents a hugely daunting task.

A similar analysis for the English NHS carried out by the King's Fund and the Institute for Fiscal Studies in 2009 (Appleby et al) of the gap between Wanless funding and productivity assumptions and zero real actual funding increases between 2011/12 and 2014/15 under the Solid Progress scenario suggested a total productivity challenge of around 27% to 2014/15 - equivalent to annual gains of around 6.2%.

The difference with the Northern Ireland estimate of 6.8% is due to the assumption of a 9% greater need for Northern Ireland (applied at the margin).

Actual policy to address the productivity gap in England has, however, evolved from an original assessment of the funding gap based on the Department Health's own analysis in 2009 (one not based on Wanless funding recommendations, based on a three, not four year time period and assuming no cash rise - ie a real cut in spending) and has taken account of subsequent policy decisions such as the two-year public sector pay freeze announced in the June Budget, planned spending announced in the spending review and a four-year time frame. As a result, the productivity challenge facing the English NHS has now been broadly assessed at around £20 billion - equivalent to around 20% by 2014/15, or about 5% per annum.

It should be noted that the Englsih productivity challenge outlined here does not include the situation facing social care over the next four years whereas the productivity challenge this review estimates facing Northern Ireland does. The funding/'need' gap that will face social care in England is very hard to estimate as local councils' actual funding and prioritisation decisions are not yet known. However, the combined challenge for health and social care will undoubtedly amount to more than the current challenge for health alone.

Improving productivity: what for?

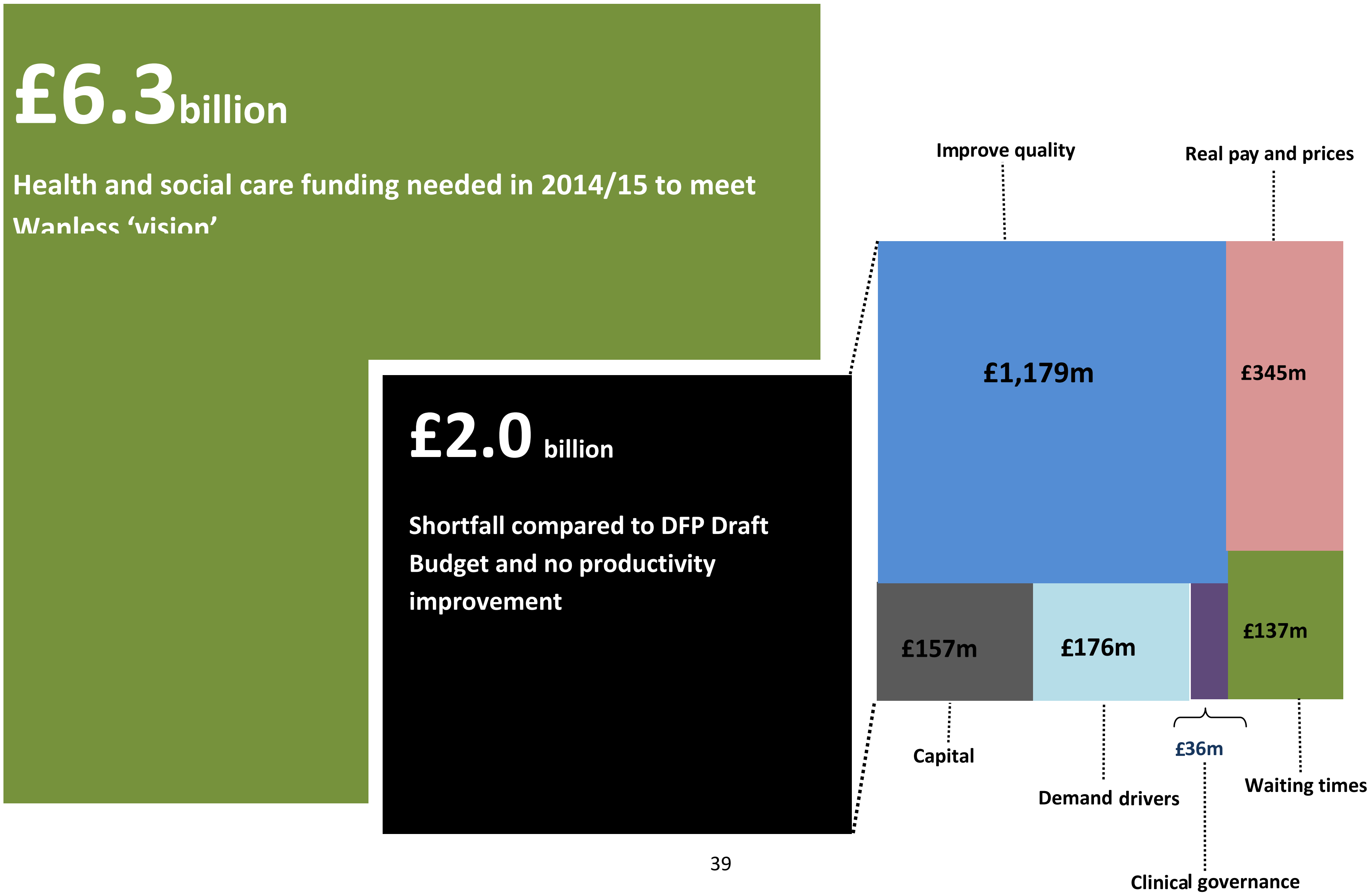
Expressing the productivity challenge in monetary terms can obscure the original 'vision' for health and social care that underpinned Derek Wanless's original funding recommendations (upon which the funding and productivity gaps reported above are based).

Wanless's starting point was to define or specify what a well-functioning, high quality health system should look like. This included a service with very short waiting times and appropriate and more widescale use of ICT - not just in 'back room' functions, but directly in terms of patients care. It also included better quality infrastructure and equipment (from hospitals to scanners), higher real pay for staff, increased activity to meet demographic and the health effects of lifestyle changes and health seeking behaviour. Importantly, it also included improved quality of care and treatment - a result of applying the best technologies, skills and treatments at the most appropriate time for patients. Wanless envisioned the roll out of disease/population-specific national service frameworks as the organisational tool for diffusing best practice throughout the NHS in order to improve quality (see Appendix 3 for details).

Given his starting point, it is possible to disaggregate the £2 billion productivity challenge into these broad elements. Figure 15 does this, based on a similar exercise for the English NHS productivity gap under the Solid Progress scenario (Appleby et al, 2009, 2010). This breakdown is not meant to represent a detailed plan for the productivity challenge in terms of Derek Wanless's vision for health and social care. Rather it illustrates in a bit more detail what being more productive is meant to achieve. In doing so it also highlights some high level decisions that could be (indeed in some cases, already have been) taken to reduce the productivity challenge. For example, the decision to freeze public sector staff pay for two years to 2012/13 will mean that the Wanless assumption of around 2.5% real terms pay increases each year through to 2014/15 will be reduced, and hence a reduction in the £345 million (roughly) estimated for increases in pay and prices in figure 15. This will in turn reduce the scale of the productivity challenge

However, the key message from the disaggregation is that the overall productivity challenge of £2 billion represents the **value** of the productivity gain - not the size of real cuts in spending or services - and that in turn, improving the **value** of services to patients (higher quality, shorter waiting etc) and ensuring services adapt and change to meet demographic and other demand pressures is the purpose of being more productive. A key challenge - and one identified by Derek Wanless's 2004 follow up report (Wanless, 2004) - is to get the balance right between actions to place downward pressure on unit costs and improvements in quality, and between necessary measures to improve productivity in the short term and action (and perhaps investment) to tackle population health problems over the longer term.

Figure 15: Disaggregating the productivity challenge: What improving productivity is meant to achieve on the basis of the Wanless 'vision' for health and social care



Summary

- Derek Wanless's funding recommendations for health care across the UK were dependent on the NHS achieving certain levels of productivity improvements. These amounted to between 12% and 20% between 2007/8 and 2014/15 depending on the Wanless scenario.

- Re-analysis of the funding gap calculations incorporating Wanless's productivity assumptions suggests - relative to the Budget for Northern Ireland - a combined funding/productivity gap of between £2 billion and £2.1 billion (on the basis of a needs differential of +9%.)

- Even if health and social care were to receive funding in line with Wanless's recommendations, this would still leave a need to achieve the productivity gains inherent in his recommended funding levels. Depending on the Wanless scenario, these would amount to between £576 million to £892 million by 2014/15 at today's prices for the +9% additional need judgement.

- Overall, the £2 billion productivity challenge facing the Health and Social Care System represents the unmet funding gap **plus** the value of the Wanless productivity assumption. It is essentially an indication in monetary terms of the additional value for money that DHSSPS would have to generate to deliver a modern, sustainable health service in 2014/15 in line with Wanless' 2002 'vision' for the system.

- A broad disaggregation of the value of the productivity gain based on Wanless's 'vision' for future health care services under his Solid Progress scenario suggests that over half the combined funding/productivity gap will need to be closed by: gains in quality, around 9% in responding to demand pressures, around 16% to improving waiting times, capital infrastructure and clinical governance and the remainder (17%) to real increases in pay and prices.

- Cutting production costs will be part of the task of achieving productivity gains - but largely as a means of freeing resources for higher value activities. However, more importantly, closing the Wanless funding gap requires improving the quality of care received by patients - improving health outcomes, reducing negatively valued attributes of care such as long waiting times etc - but within the constraints of future budgets.

SECTION 5: SYSTEM PERFORMANCE OVERVIEW

This section reviews some broad measures and indicators of productivity and performance and suggests that while the productivity gap identified in section 4 represents a huge challenge, there should be scope for improving value for money in health and social care in Northern Ireland.

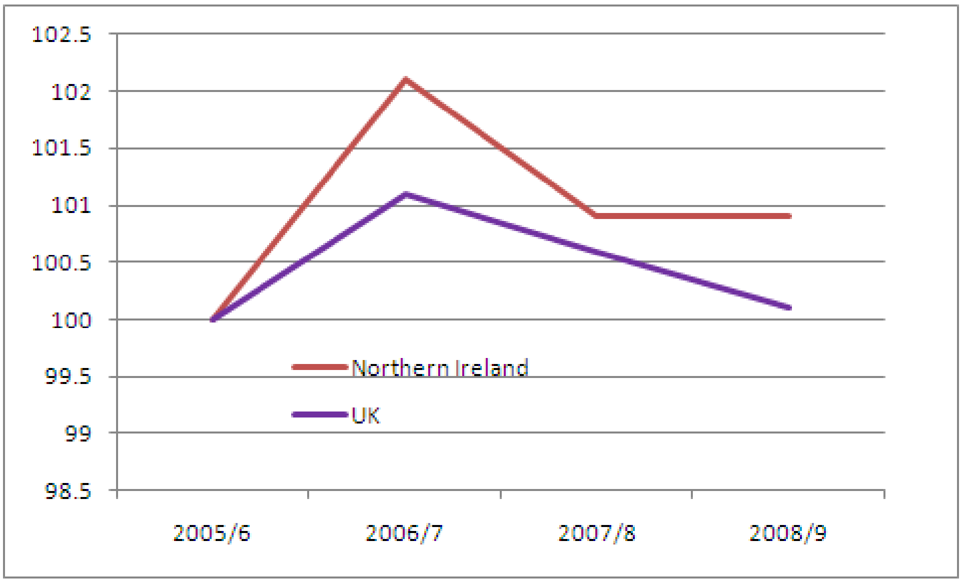
The service areas covered in this section are not, of course, exhaustive. In particular, the nature of data availability inevitably means there is a bias towards secondary care services. This should not be taken as any indication that potential productivity gains are limited to this sector. As the McKinsey analysis for DHSSPS showed (McKinsey, 2010), community services, primary care and social services all have their share of the potential to improve productivity - although opportunities for improving productivity may not be spread equally across sectors.

System-wide productivity measures and indicators

The Office of National Statistics produce measures of UK NHS productivity annually. However, work on disaggregated measures for Northern Ireland are ongoing. Nevertheless, for this review, DHSSPS have produced a broadly equivalent productivity measure for Northern Ireland (see Appendix 4 for details). The comparisons with the ONS UK measure in the figures below should, however, only be taken as indicative.

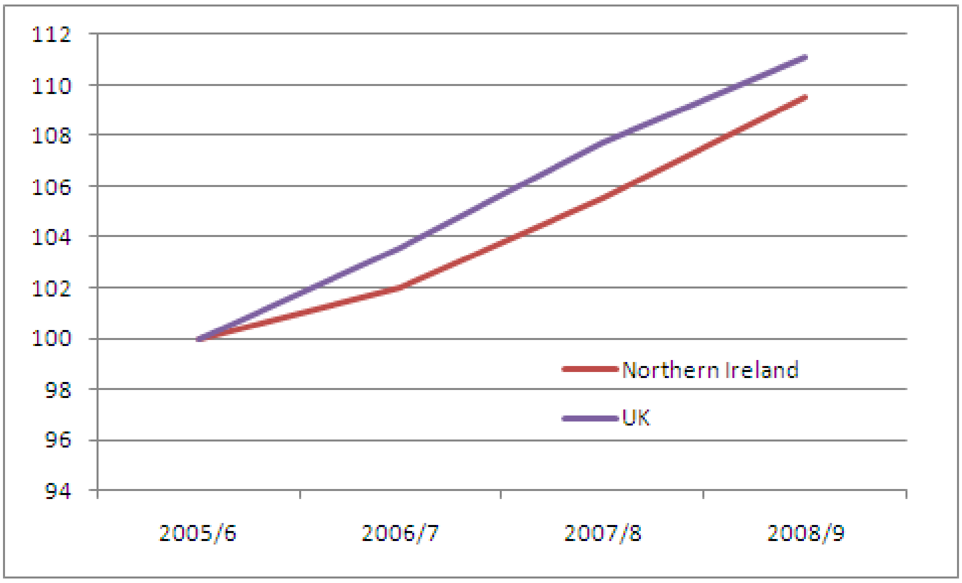
Figure 16 shows that Northern Ireland increased its productivity between 2005/6 and 2008/9 by just under 1%. The UK, on the other hand, increased productivity by a fraction of a percent.

Figure 16: NHS productivity: NI and UK



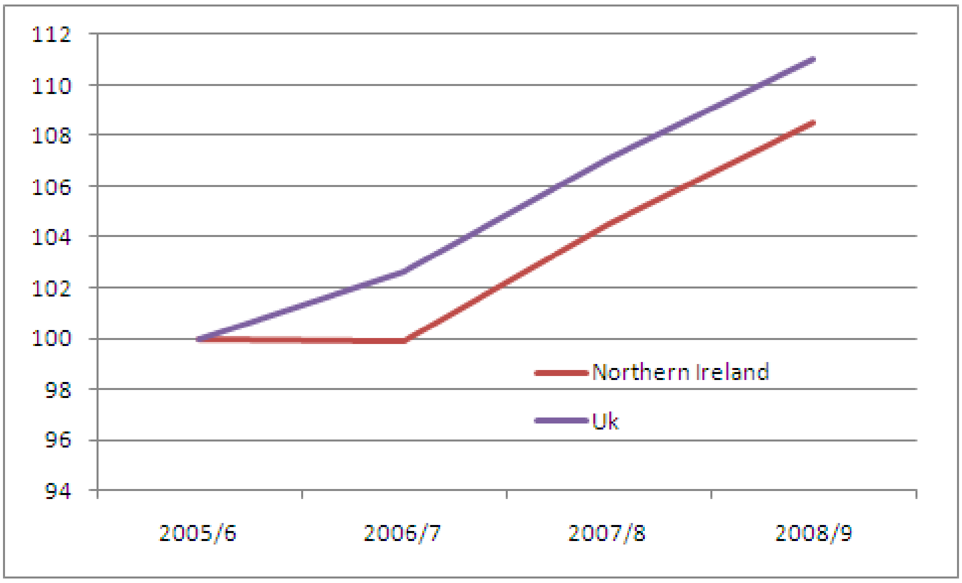
However, the NHS across the UK recorded a faster growth in outputs than Northern Ireland (see figure 17).

Figure 17: Output change: NHS NI and UK



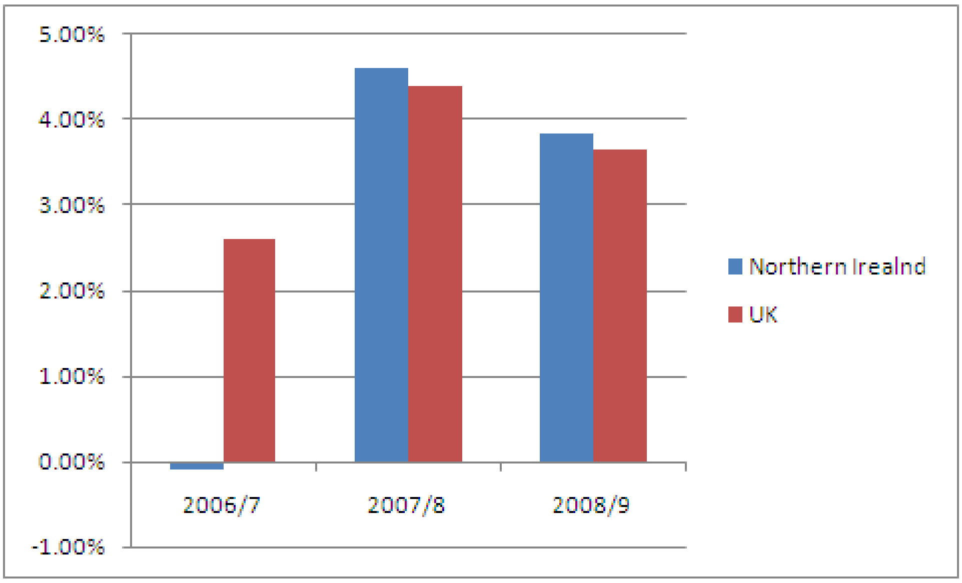
The reason Northern Ireland reported a greater productivity gain was due to its slower growth in inputs (figure 18).

Figure 18: Input change: NHS NI and UK



In fact, the slow growth in inputs relative to the UK was due to just one year - 2006/7 (and in one element of inputs, Goods and services - see figure 19).

Figure 19: Annual percentage change in volume of NHS inputs NI and UK

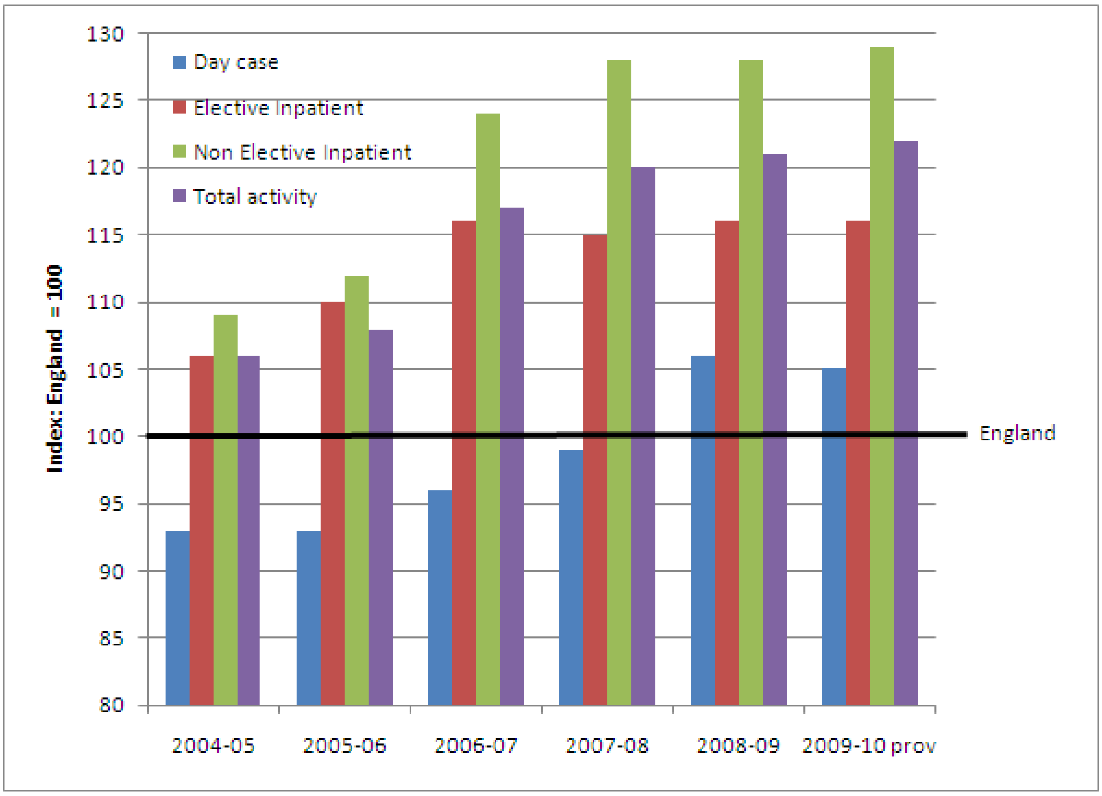


The main conclusion that should perhaps be drawn from these data is the relative lack of improvement in productivity in Northern Ireland and the UK generally. Further, historically changes in productivity across the UK have been most correlated with changes in inputs rather than changes in outputs; as financial inputs grow more slowly, outputs (for a time at least) carry on growing and hence productivity increases. The slowdown in the growth in funding over the next four years might well therefore lead to an increase in productivity in the short term, but is not sustainable without improvements in output growth.

Unit costs

Another aspect of productivity is the costs of production. Figure 20 provides a comparison between Northern Ireland and England for three types of hospital activity - elective and non-elective inpatients and day cases. The comparison is based on using English unit costs by healthcare resource group (HRGs) and Northern Ireland activity. Figure 20 suggests that Northern Ireland has generally become progressively more costly relative to England from 2004/5 to 2009/10 in all three areas of activity (except for day casess in 2009/10 - though this year's data is provisional). By 2008/9, while the costs of producing a day case were around 6% higher than in England, the costs for elective inpatients were 16% higher and for non-elective cases, nearly 28% higher. Across all areas of activity, Northern Ireland costs were just over a fifth more expensive. It should be noted that the move to a new HRG classification system in 2006/7 may account for part of the increase in relative costs between 2005/6 and 2006/7, with subsequent years perhaps more accurately reflecting an existing differential between Northern Ireland and England not properly captured before 2006/7.

Figure 20 HRG index for Northern Ireland. England =100



NB: HRGs cover acute, maternity and elderly medicine specialties only

A similar analysis - multiplying English HRG unit costs by Northern Ireland activity - for providers shows considerable variation, while nearly all hospitals record 'excess' total costs in relation to England (see figures 21 to 26).

Figure 21: Elective inpatients: Provider 2008/9

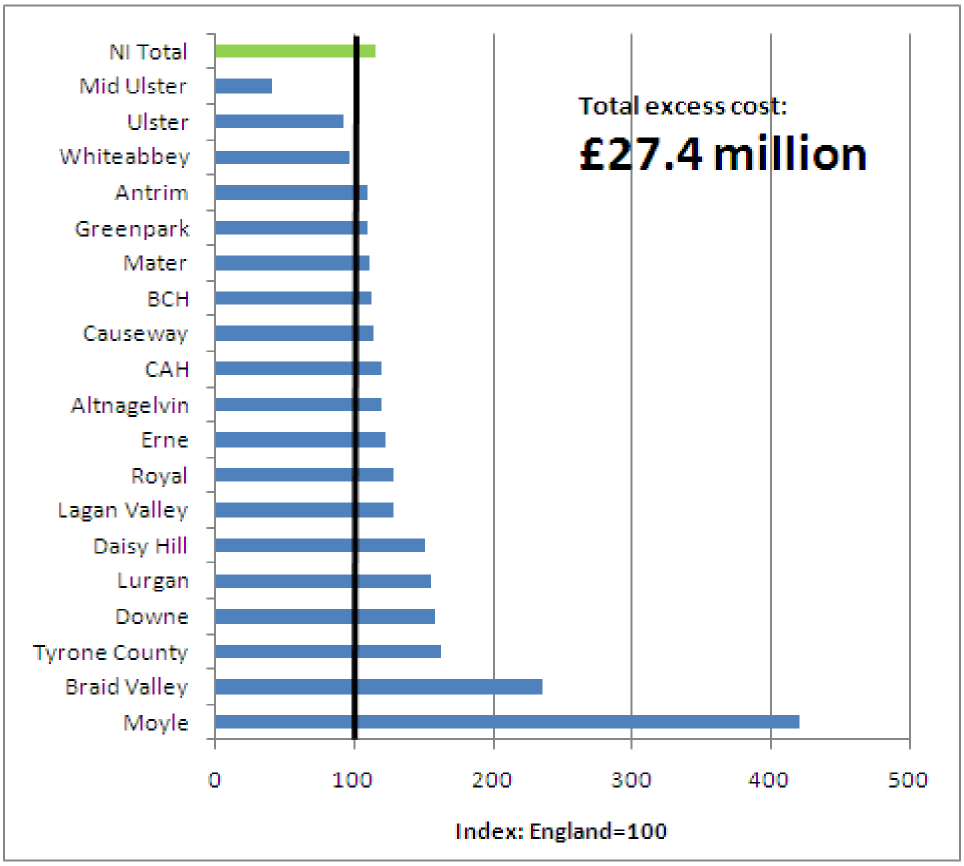


Figure 22: Non-elective inpatients: Provider 2008/9

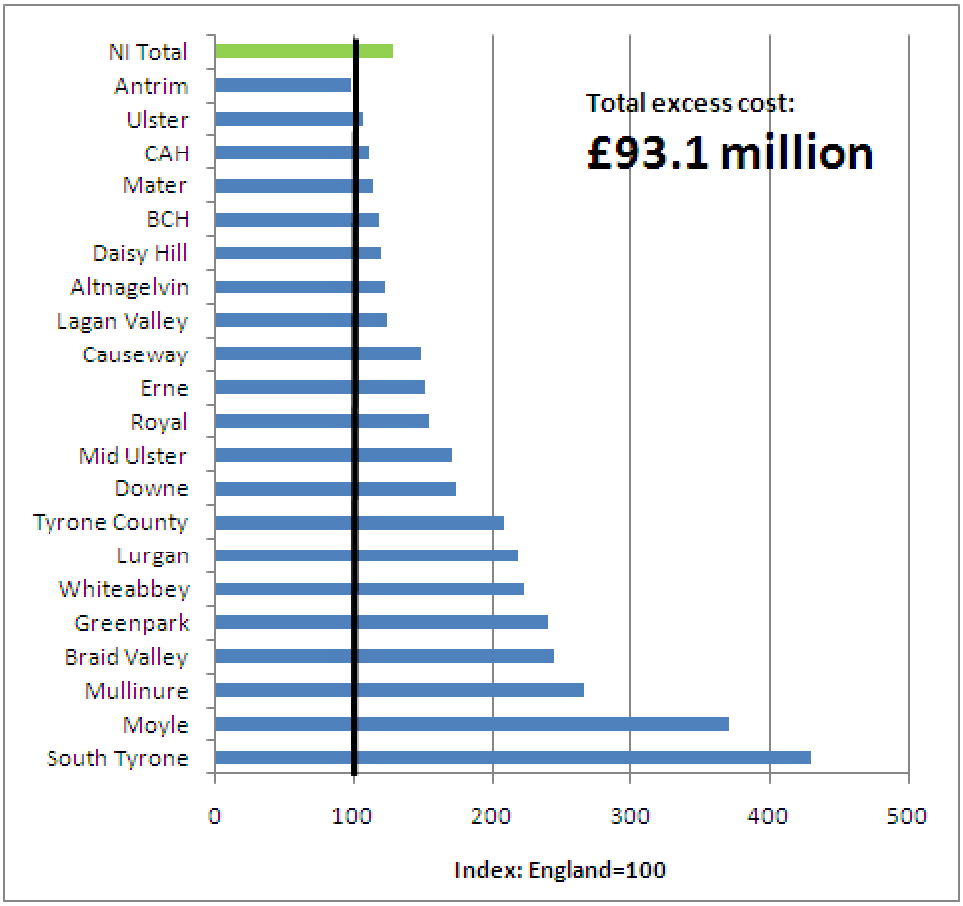


Figure 23: Day cases: Provider 2008/9

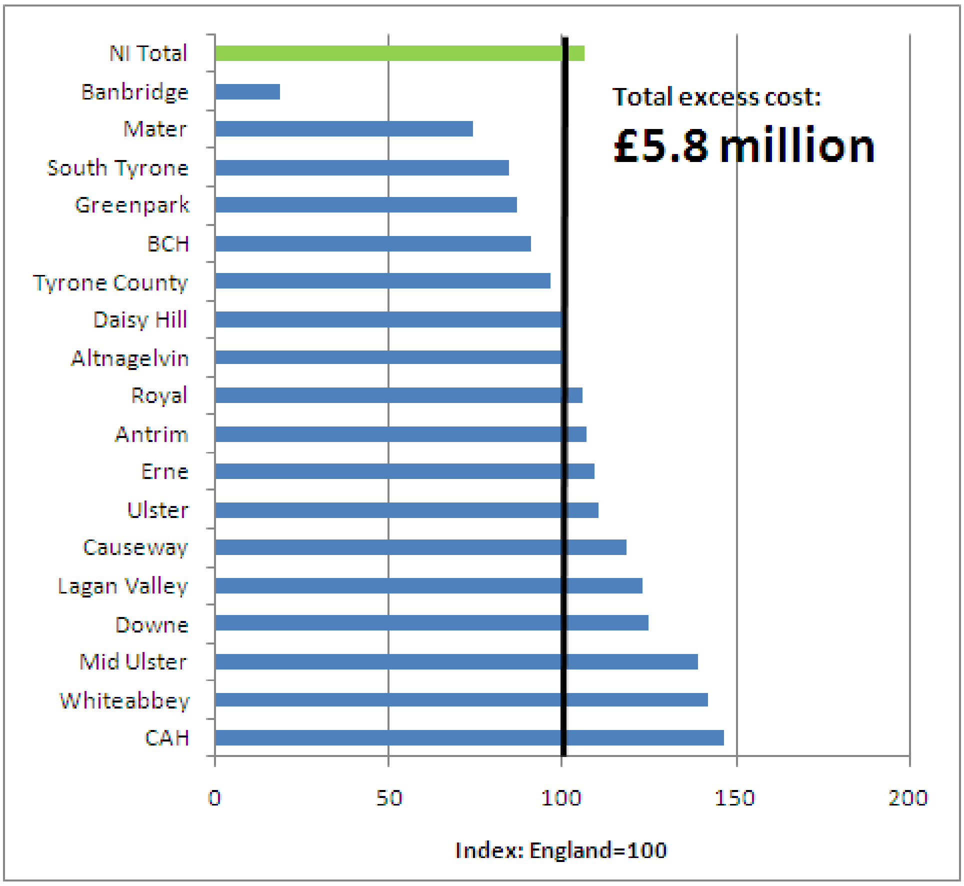


Figure 24: Total: Elective, non-elective, day case, by provider 2008/9

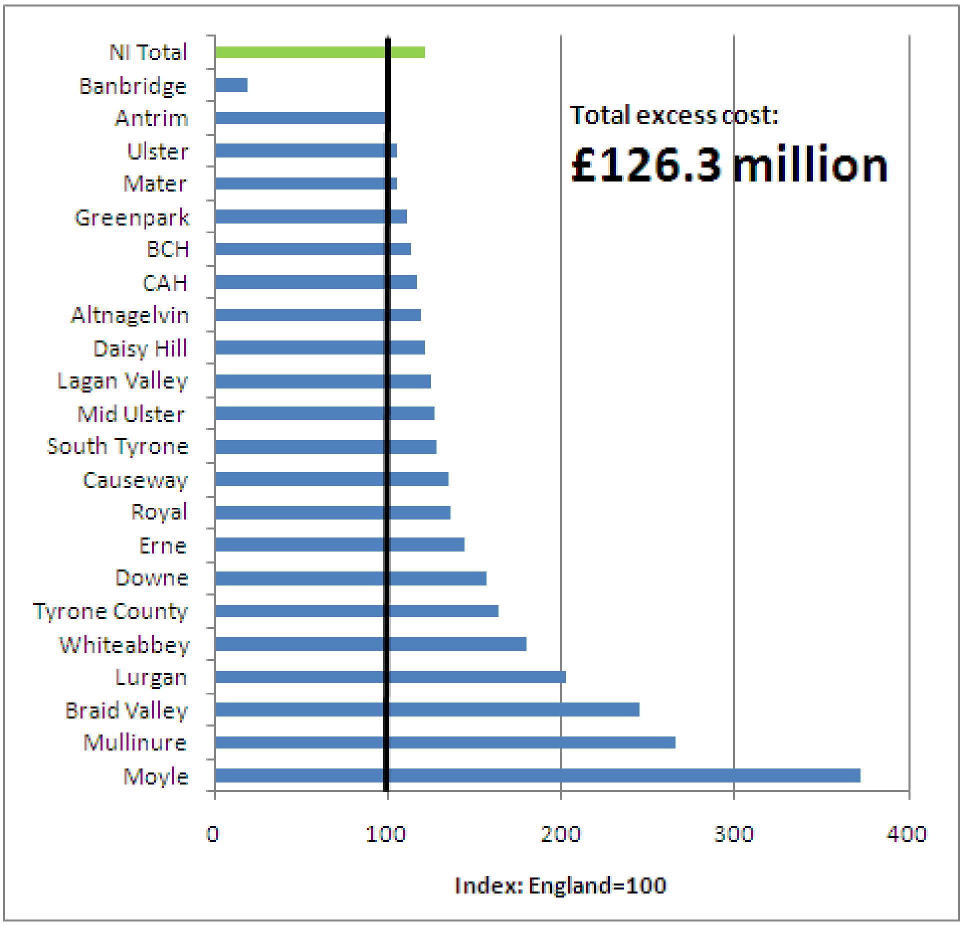


Figure 25: Total: Elective, non-elective, day case, by trust 2008/9

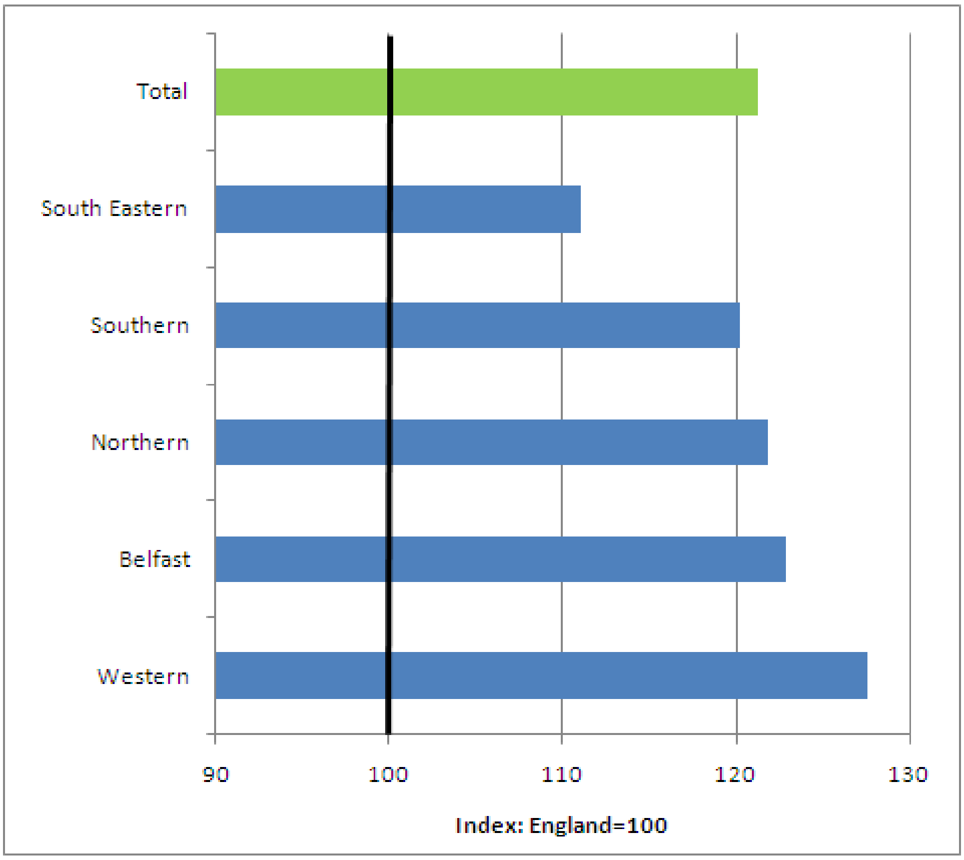
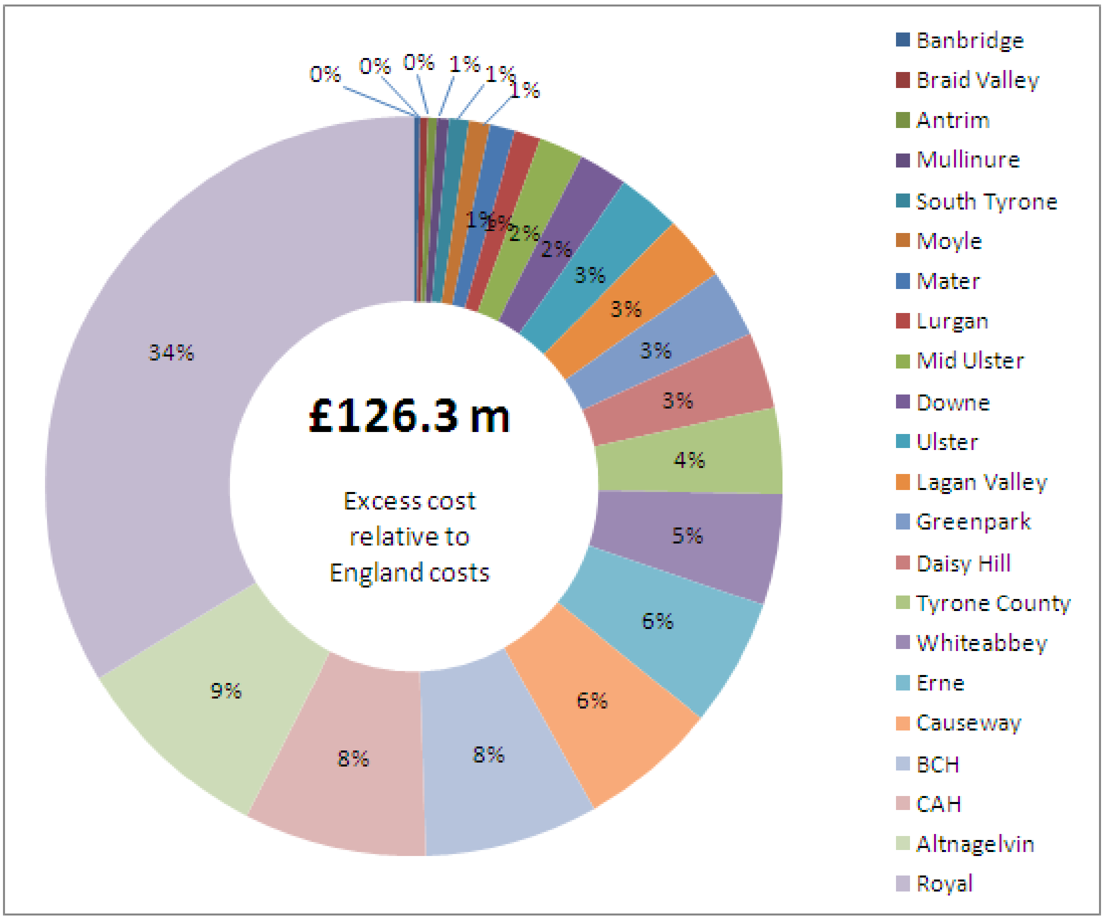


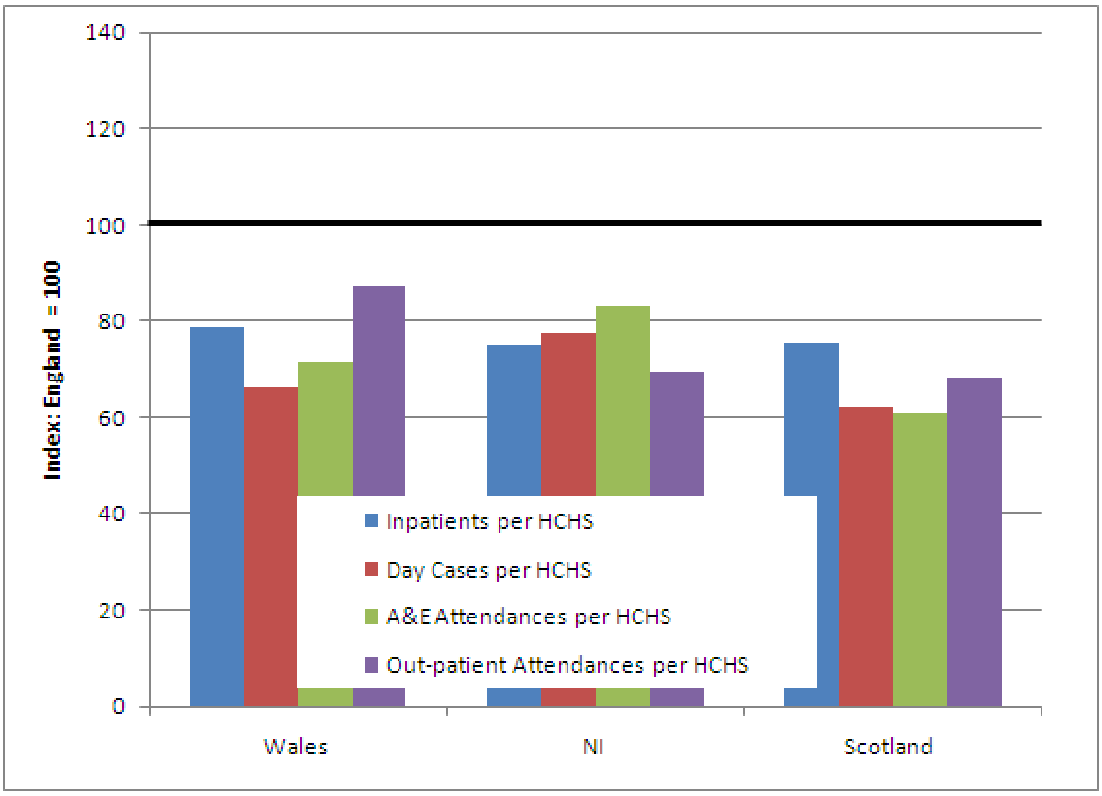
Figure 26: Total excess cost by provider 2008/9



Workforce productivity

Basic measures of workforce productivity also provide an indication of relative productivity across the UK. Figure 27 shows, for example, that Northern Ireland staff productivity for inpatients, day cases, accident and emergency and outpatient activity is between 17% and 30% lower than England.

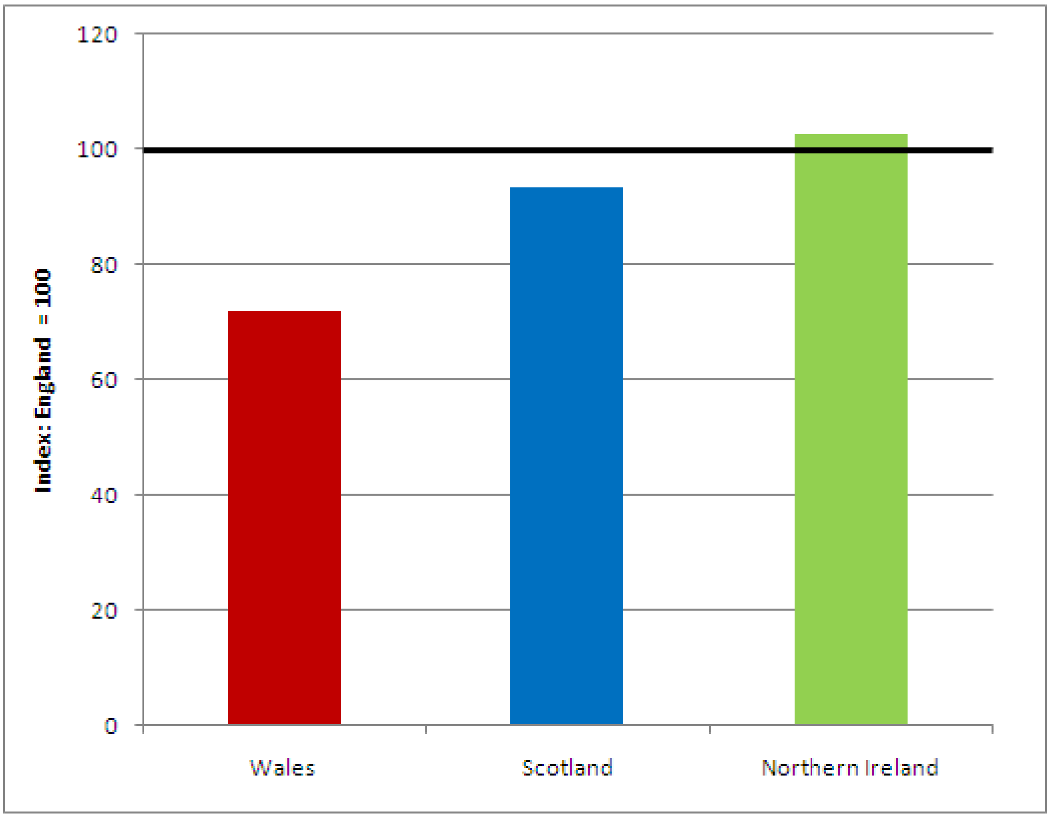
Figure 27: Acute activity per head of hospital and community health service staff: 2008/9



NB: Data for accurate specialties only

However, consultant productivity appears to be around 2% higher in Northern Ireland than in England (see figure 28). However, in all countries trends on this crude productivity measure have been downward for many years.

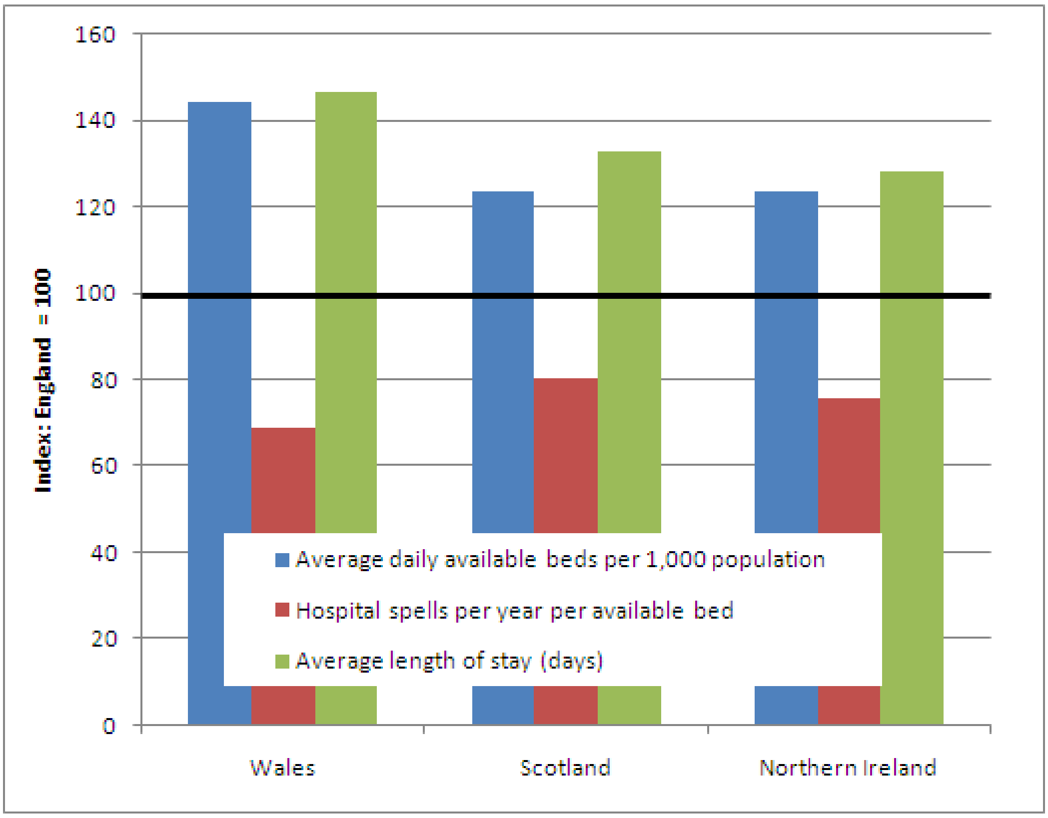
Figure 28: Acute finished consultant episodes per whole time equivalent consultant: Relative to England: 2009/10



Hospital bed use

Northern Ireland has approximately a quarter more acute beds per 100 population than England (see figure 29). However, these beds are less intensively used - 55 inpatient spells per bed per year compared with 72 for England. Further, patients tend to stay in hospital for longer periods - nearly 28% (1.2 days) longer than the average English patient.

Figure 29: Beds, activity per bed and average length of stay relative to England: Acute specialties, 2008/9



NB: Elderly care is not included in any of the data

Waiting times

For patients, having to wait and in particular, having to wait excessively long times to receive treatment in hospital, is a very visible indicator of a health system not working efficiently. Following a steady rise in the numbers on outpatient waiting lists from 1996 to 2006, considerable efforts to reduce list sizes resulted in a huge reduction in numbers waiting - from around 180,000 (then, more one in ten of the entire Northern Ireland population) to around 68,000 in 2009 (see figure 30). However, since then numbers waiting for their first appointment at an outpatients department has risen, and at a faster rate than during the decade from 1996. Numbers waiting have now doubled to around 124,000 by December 2010 (although December shows a slight downturn).

Similar trends can be seen with the inpatient waiting list which has now risen to 51,000 from a low of 35,000 in 2007.

While lists have lengthened, so too have the time patients have had to wait. Figure 31 for outpatients shows that while waiting over three months was virtually eradicated by 2008, numbers waiting between 3 and 6 months now stand at around 27,000, and those waiting over half a year at over 10,000.

Figure 30: Inpatient and outpatient waiting lists: 1994-2010

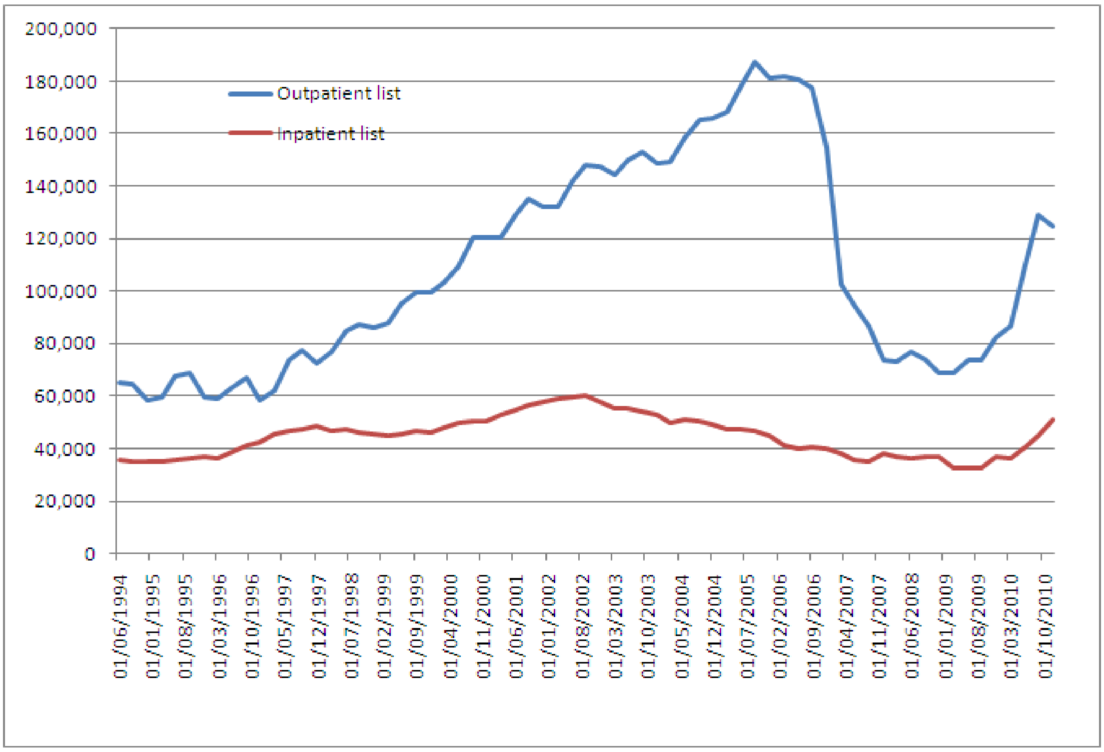
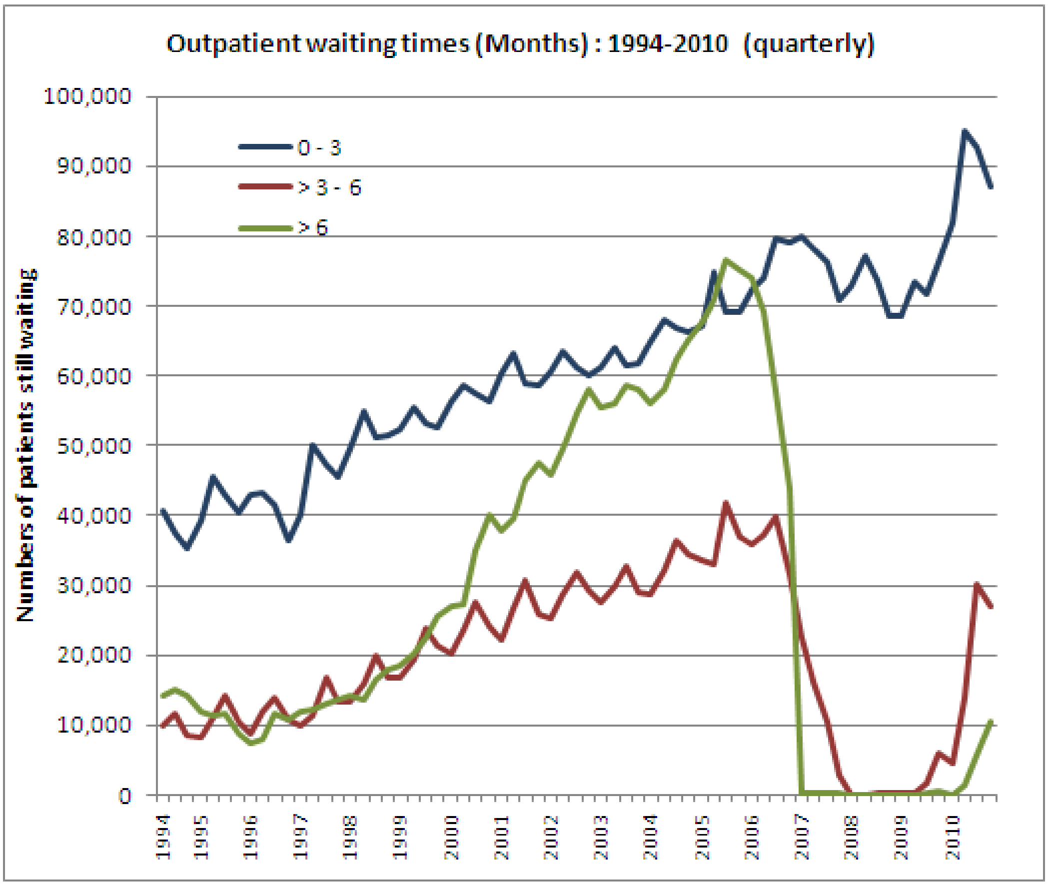
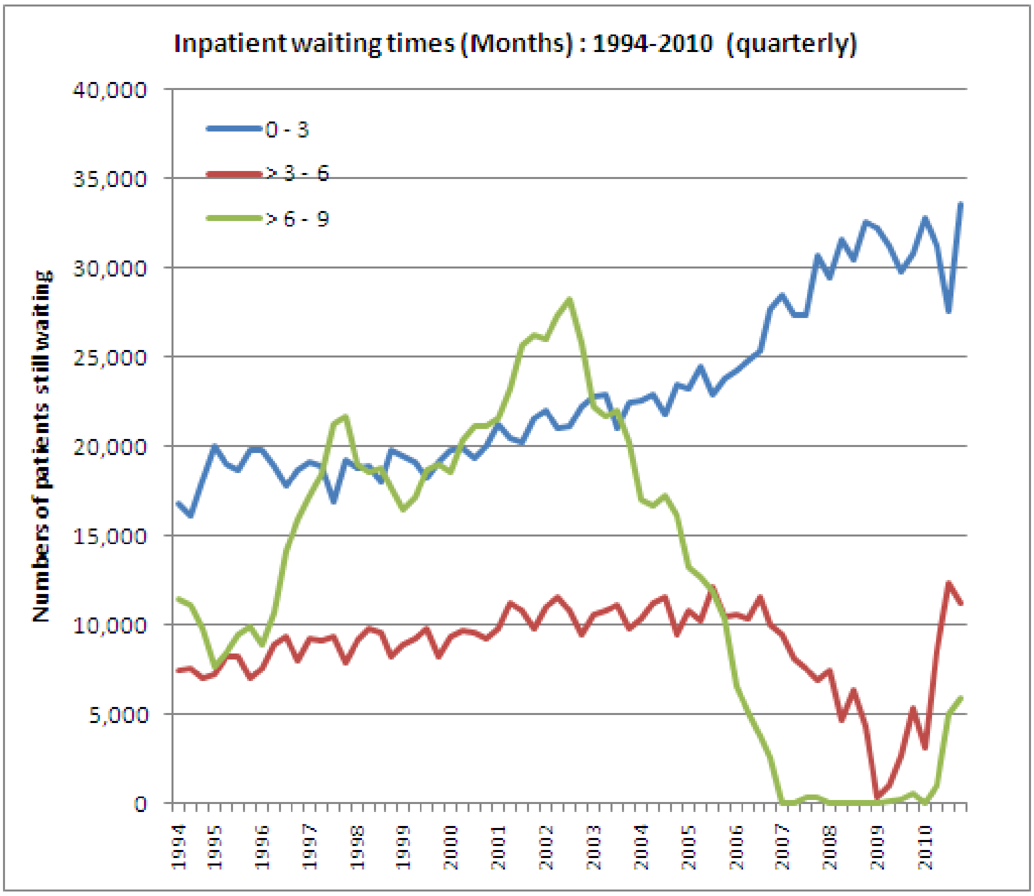


Figure 31: Outpatient waiting times: 1994-2010



Similarly, waiting times for patients on inpatient lists are also creeping up (see figure 32). Having briefly reduced the number of patients waiting 3 to 6 months to zero in 2009, there are now over 11,200 waiting this long. There are also around 5,900 patients now waiting over half a year to be admitted.

Figure 32: Inpatient waiting times: 1994-2010

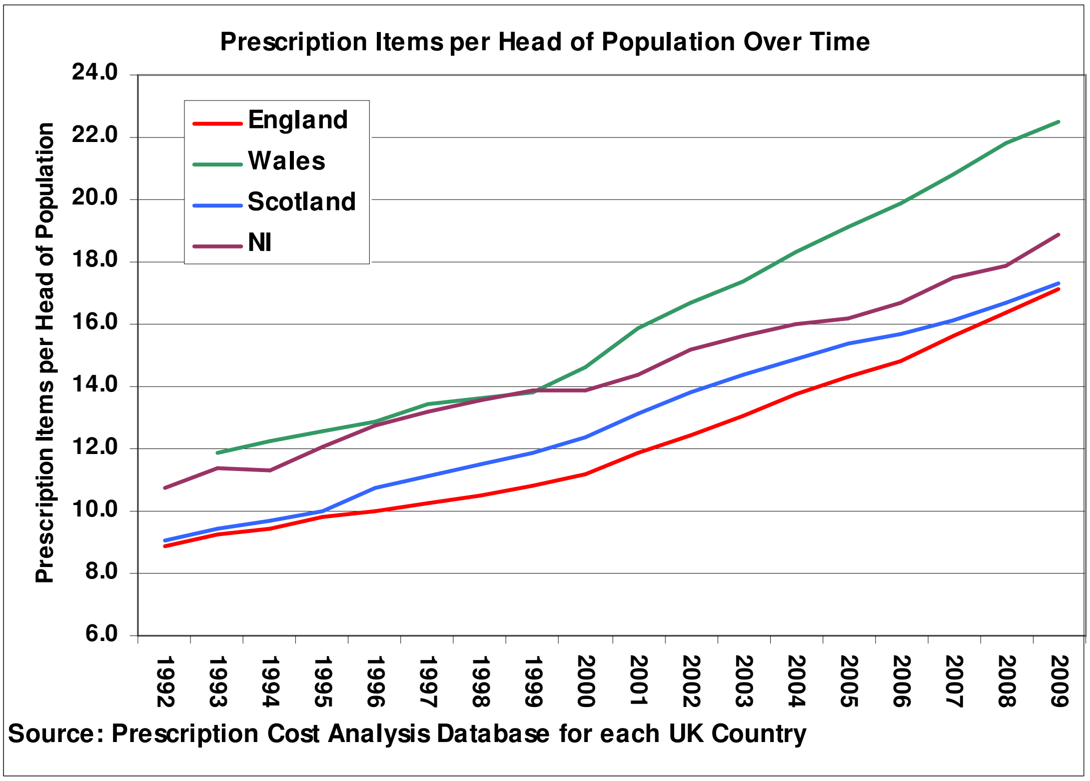


In addition, during the quarter ending 31 December 2010, while 81% of new and unplanned review attendances at A&E units (includes A&E and Minor Injury Units (Type 1, 2, 3)) in Northern Ireland were either treated and discharged or admitted within 4 hours of their arrival at A&E, this compared with 97% in England.

Pharmaceutical services

Prescribing rates in Northern Ireland remain around 12% higher per head of population than England and Scotland (see figure 33).

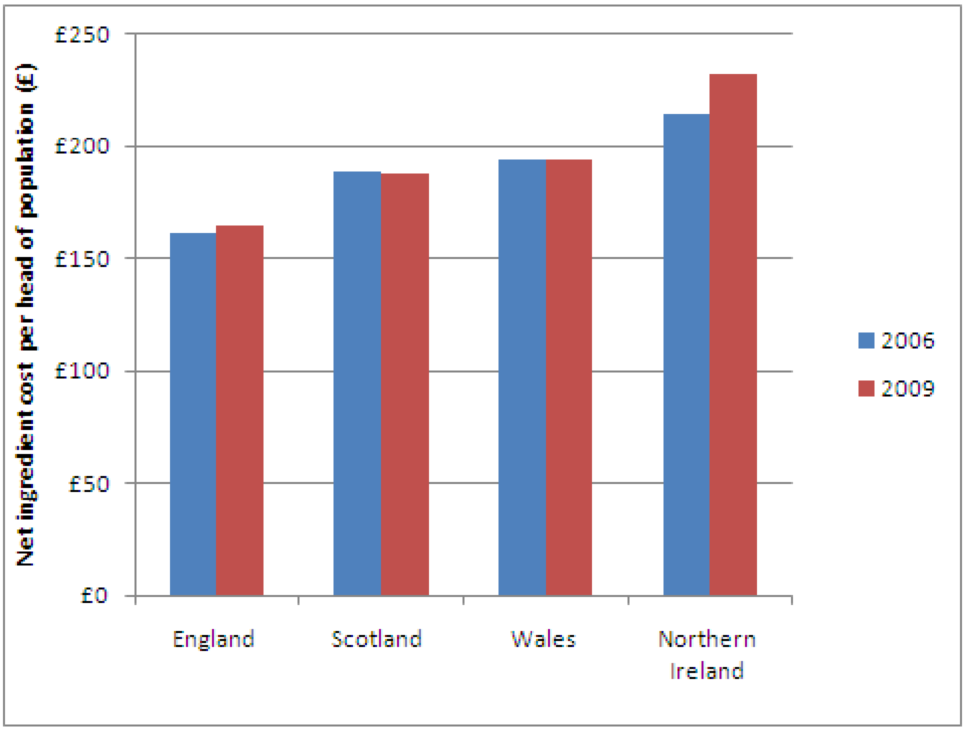
Figure 33: Prescription items per head of population: UK trends



Source: Prescription Cost Analysis Database for each UK Country

However, generic dispensing rates have increased from around 50% in 2007 to around 62% in 2010 in Northern Ireland. Currently generic dispensing rates in England are around 68%. Despite this, the net ingredient cost of prescriptions per head of population in Northern Ireland remain relatively high - 31% higher than England in 2006 - and increasing at a faster rate - 8.3% between 2006 and 2009 compared with 2.2% in England (see figure 34).

Figure 34: Net ingredient cost per head of population: 2006 and 2009



Summary

- A system-wide measure of productivity for the Northern Ireland NHS suggests a small increase of productivity between 2005/6 and 2008/9 of just 1% - achieved largely from one year's slow down in input growth rather than growth in outputs over inputs.

- Applying England's unit HRG costs to Northern Ireland activity reveals large 'excess' costs of production: Provisional data for 2009/10 shows: Elective inpatients, 16% excess costs; non-elective inpatients, 29%; day cases, 5%. Overall, costs were 22% higher.

- There is considerable variation across providers when applying England's unit costs to their activity. Some hospitals appear to incur more than twice the cost that would be expected if they operated at England's unit HRG costs for elective inpatients.

- The total estimated 'excess' cost for elective and non-elective inpatient and day case activity was around £126 million in 2008/9.

- Accurate comparative data on workforce productivity has been difficult to produce. However, indicative data suggests Northern Ireland produces between 17% and 30% less inpatient, outpatient, day case and A&E activity per head of HCHS staff than England.

- Northern Ireland has over 20% more acute beds than England, but these are used less intensively; throughput per bed is around 25% lower than that achieved in England. Patients also stay in hospital around 28% (1.2 days) longer than patients in England.

- Waiting lists for inpatients and outpatients are now rising rapidly since significant falls from 2006 to 2009.

- Around 5,900 patients are waiting over half a year year for admission to hospital as an inpatient and over 10,000 are still waiting over half a year for their first outpatient appointment.

- Pharmaceutical costs have risen faster in Northern Ireland than anywhere else in the UK between 2006 and 2009 - net ingredient costs per head of population have risen by over 8% and are now 40% higher than in England.

- Generic dispensing continues to improve - from around 50% in 2007 to 62% in 2009. This compares to 68% in England.

REFERENCES

Appleby J (2005) Independent Review of Health and Socvial Care Services in Northern Ireland. Belfast, DHSSPS
http://www.dhsspsni.gov.uk/show_publications?txtid=13662

Appleby J, Crawford R, Emmerson C (2009). *How Cold Will It Be? Prospects for NHS funding: 2011-2017*. London: The King's Fund / Institute for Fiscal Studies.

Appleby J, Ham C, Imison C, Jennings M (2010). Improving NHS productivity: More with the same, not more of the same. London, The King's Fund
http://www.kingsfund.org.uk/publications/improving_nhs.html

Bamford D (2007) Bamford Review of Mental Health and Learning Disability. Belfast, DHSSPS.
http://www.dhsspsni.gov.uk/bamford.htm/

Daily Telegraph (2009) 'IMF puts total cost of crisis at £7.1 trillion'
http://www.telegraph.co.uk/finance/newsbysector/banksandfinance/5995810/IMF-puts-total-cost-of-crisis-at-7.1-trillion.html

HMT (2010) Spending Review 2010 Cmnd 7942, London, TSO
http://www.hm-treasury.gov.uk/spend_index.htm

Institute for Fiscal Studies (2011) IFS Green Budget. February 2011. London, IFS.
http://www.ifs.org.uk/publications/5460

McKinsey (2010) Reshaping the System. Belfast, DHSSPS
http://www.dhsspsni.gov.uk/index/mckinseyreport.htm

Morris S et al (2007) Combining Age Related and Additional Needs (CARAN) Report: 2007 review of the needs formulae for hospital services and prescribing activity in England. London, ACRA/Department of Health.
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093169.pdf

Northern Ireland Executive (2011) Budget 2011-2015. Belfast, Northern Ireland Executive.
http://www.northernireland.gov.uk/revised_budget_-_website_version.pdf

Rosato, M. and O'Reilly, D., 2006. *Should uptake of state benefits be used as indicators of need and disadvantage?*, Health and Social Care in the Community Vol 14 (4), pp. 294-301.

The Poverty Site (2011) Northern Ireland: Disability Living Allowance recipients
http://www.poverty.org.uk/i15a/index.shtml

The Scottish Government (2010) Scotland's spending plans and draft budget 2011/12. Edinburgh, The Scottish Government.

http://www.scotland.gov.uk/Publications/2010/11/17091127/0

Wanless D (2002) *Securing our Future Health: Taking a long term view. A final report.* London: HM Treasury.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009293

Wanless D (2004) Securing good health for the whole population: Final report London: HM Treasury
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4074426

Welsh Assembly (2011) Final Budget February 2011. Cardiff, Welsh Assembly hhttp://wales.gov.uk/about/budget/finalbudget2011/?lang=en

APPENDIX I

Relative needs model descriptions

HMT NAS model

The NAS model employs a similar methodology for HCHS, FHS and PSS components of expenditure but differs in the groupings used to define population demographics, the chosen indicators of need and the costs of delivering services. The key components to the NAS model are

HCHS

- Population structure - the population is broken down by births and 7 selected age bands (0-4 through to 85+) and weighted by English HCHS expenditure weights.
- Morbidity - measured using SMR < 75 with a weighting of 0.6.
- Deprivation – based on a composite indicator consisting of 3 equally weighted factors: Isolated Elderly, Housing Conditions, and Income Support.
- Fertility – a measure of the average number of children that women would have over child bearing years assuming age-specific fertility rates.
- Sparsity – Proportion of people living in District Council areas with a population density of less than 1 person per hectare.
- Resource cost differences – based on additional HCHS expenditure experienced in Thames regions of England compared to total English HCHS allocation.
- Teaching Expenses adjustment

The factors are applied to the following percentage of expenditure:

Population structure: 100%
Morbidity: 77%
Deprivation: 7.5%
Fertility: 6%
Sparsity: 12.5%

FHS

- Population structure – Similar procedure to HCHS but using five age categories (0-4, 5-15, 16-64, 65-74, 75+) and weighted by English FHS expenditure weights.
- Morbidity – combination of SMR < 75 and an indicator of the percentage of population in physically demanding (manual) occupations. The two factors are weighted in ratio 0.8:0.2.
- Deprivation – based on a composite index consisting of the following factors: Isolated Elderly, Housing Conditions, IS recipients, Children in Lone Parent Families on IS, and Children in Lone Parent Families. The relative weightings applied to these are 0.3, 0.1, 0.4, 0.1, and 0.1 respectively.
- Fertility – as HCHS

- Sparsity - calculated by expressing total GMS expenditure including expenditure on Rural Practice Payments (RPPs) as a percentage of GMS expenditure without RPPs.

The factors are applied to the following percentage of expenditure:

Population structure: 100%
Morbidity: 40%
Deprivation: 30%
Fertility: 6%
Sparsity: 28%

PSS

(1) Elderly (population aged 65+):

- Population structure – divided into 3 sub-groups (65-74, 75-84, 85+) and weighted using weights 1.0, 4.5 and 14.2 respectively.
- Deprivation – Composite index consisting IS recipients, Isolated Elderly and Housing Amenities. The three factors are weighted in ratio 0.3, 0.6, 0.1 respectively.
- Disability – prevalence of disability among adult population.
- Sparsity – as with HCHS
- Resource cost differences – based on comparison of average earnings of PSS professionals.

The factors are applied to the following percentage of expenditure:

Deprivation: 50%
Disability: 2%
Sparsity: 50%

An overall index is calculated by multiplying the following factors: Population; Deprivation, Disability and Sparsity; and Resource cost differences.

(2) Children (< 18):

- Population structure – single weight applied to under 18 age group.
- Deprivation – composite index consisting of IS recipients in under 60 age group, Children in Single Parent Families (2 versions of), Housing Conditions, Population density. These factors are weighted in ratio: 0.2, 0.125, 0.125, 0.05 and 0.5 respectively.
- Disability – as per PSS Elderly.
- Sparsity – as per PSS Elderly
- Resource Cost Difference – as per PSS Elderly.

The factors are applied to the following percentage of expenditure:

Deprivation: 60%
Disability: 2%
Sparsity: 50%

An overall index is calculated by multiplying the following factors: Population; Deprivation, Disability and Sparsity; and Resource cost differences.

(3) Other:

- Population structure – single weight applied to 18 to 64 year age group.
- Deprivation – composite index consisting of IS recipients in under 60 age group, Children in Single Parent Families (2 versions of), Housing Conditions. These factors are weighted in ratio: 0.5, 0.2, 0.2, and 0.1 respectively.
- Disability – as per PSS Elderly.
- Sparsity – as per PSS Elderly
- Resource Cost Difference – as per PSS Elderly.

The factors are applied to the following percentage of expenditure:

Deprivation: 30%
Disability: 2%
Sparsity: 50%

An overall index is calculated by multiplying the following factors:
Population; Deprivation, Disability and Sparsity; and Resource cost differences.

An overall need factor for PSS is calculated by averaging the needs factors for the three sub-programmes using weights that are proportions of total PSS spending in England on each group. The weights are 46% for elderly, 34% for children and 20% for other adults.

Northern Ireland Capitation formulae

The individual formula from the nine programs of care from the NI regional capitation model were combined with the Drugs Bill in the Prescribing and Pharmaceutical Budget and the GMS allocation formula, the weights used are shown in Table 1 below.

Table 1 Expenditure data used for 2010-11 modelling excluding Capital Charges and Negligence

Programme of Care	**Expenditure Weights**
Acute Services Elective	20.02%
Acute Services Non Elective	15.66%
Maternity and Child Health	3.73%
Family and Child Care	5.67%
Elderly Care	17.90%
Mental Health	7.00%
Learning Disability	6.23%
Physical and Sensory Disability	2.65%
Health Promotion and Disease Prevention	2.92%
Primary Health and Adult Community	3.32%
Global sum	3.32%
Drugs bill in Prescribing and Pharmaceutical budget	11.59%
Total	**100%**

Each of the Individual Programmes are discussed below.

Elective Acute Services

Age effect

This is a two stage multiplicative model. The age-gender weights for this formula are set for 18 5 year age bands from 0-4 up to 85+ they are given in Table 3 below.

Additional need

The additional need for this POC is calculated as:

(Proportion of 65+ not claiming AA) ^-0.172 (Standardised limiting long term illness) ^0.173 *(Standardised cancer incidence rate) ^0.095 * (Standardised Birth rate 2000-2004) ^0.155 * (Proportion of households not owned outright) ^0.146 **
*(Pro households with 2 or less children) ^-0.460 * (Proportion of females 45-64) ^0.109*

Non Elective Acute Services

Age effect

The age-gender weights for the non-elective acute are for the 18 5 year age bands as discussed in the elective formula the weights are given in Table 4

Additional need

The calculation of the additional needs index for the non elective acute formula is as:

(Pro 65+ not claiming AA) ^-0.312 (Standardised self reported not good health) ^0.248*(Replacement for NI MDM 2005) ^0.093* (Standardised Birth rate 2000-2004) ^0.185*(Pro household not owned outright)^0.217*

The original result from research for this formula included the overall Northern Ireland multiple deprivation measure from 2005 in the model, however, this indicator is unavailable for England. In order to overcome this problem Demography and Methodology Branch (DMB) of the Northern Ireland Statistics and Research Agency (NISRA) recommended that a population weighted average of the income domain could be used in place of this indicator.

Maternity and Child Health

In this PoC there are no age gender weights, however, weightings are applied to births and the 0-4 population separately and then combined to give the overall allocation.

Additional need

The age of the mother is taken into consideration in the calculation of the needs index for births. All calculations involved in births weightings are given below.

Table 2 Calculation of additional needs index for Maternity and Child Health

Age of mother / indicator	25-29	30-34	35-39	40-44	LBW	Mult Birth	Prev Births
Coefficient	0.312	0.609	0.898	0.973	7.152	1.891	-1.477

Standardised mortality rates for those aged under 75 years are used as the additional needs index for the 0-4 population resulting in an increased share for NI.

Family and Child Care

Age effect

The age gender weights for this PoC are based upon four age bands 0-4, 5-9, 10-14, 15-19 and 20-44 they are included in Table 5.

Additional need

The calculation of the additional needs is as:

(Propn 16-18 yr olds not in F-T Ed)^0.205 (Prop children in Own Occ Hsing)^-0.599* (Prop children in IS hholds)^0.448*

In the original capitation formula for this PoC the Noble Social Environment score was a needs variable. As it was not possible to give overall scores for England and NI for this variable, the coefficients on the remaining needs variables were re-estimated.

Elderly Care

Age effect

The age weights for this PoC are based upon age bands of 65 to 69,70 to 74, 75 to 79, 80 to 84 and 85 and over, they are given in Table 6.

Additional need

The calculation of the additional needs index is as:

(Pro elderly females under 85)^1.479 (SMR 65 and over)^0.128*
(65+ not claiming AA)^-0.946 (Pro pensioners not in social housing)^-0.152*
(Potential years of life lost)^0.069

Mental Health

Age effect

The age-gender weights for this PoC are based upon seven age bands for the whole population and are given in Table 7 below.

Additional need

The calculation of the additional needs index is as:

*(Proportion of 16-64 year olds on Income Support) ^0.365**
*(Proportion of dependents not in single carer households) ^-1.393**
*(Proportion of persons in households with head in manual class) ^0.340**
*(Proportion of working age population who are students) ^0.250**
(Standardised Mortality Rates for those aged 65-74)^0.268

Learning Disability

Age effect

The age weights for this PoC are based upon the following four age bands 0-19, 20-34, 35-49 and 50+ they are given in Table 8

Additional need

The variables used in the calculation of the additional needs index are given in the table below.

*(Proportion of Persons in No Carer Households (where at least one person has a self-reported long-standing illness))^0.745**
*(Proportion of Children In Job Seekers Allowance Households)^1.452**
*(Proportion of Persons Aged 16-64 with no Qualifications)^0.587**
*(Proportion of Persons in Households without Central Heating)^0.914**
(Proportion of Children in Disability Living Allowance Households)^2.671

Physical and Sensory Disability

Age effect

The age gender weights in this PoC are based upon the age bands 0-24, 25-44 and 45-64 and are shown in Table 9.

Additional need

The variables used in the calculation of the additional needs index are given in the table below.

*(Standardised Limiting Long Term Illness (<65))^0.559**
*(16-64 year olds living in Disability Allowance Households) ^0.376**
(Noble Income Domain) ^0.114

Health Promotion and Disease Prevention

There are no age-gender weights in this PoC. To adjust for need, the total population is weighted by the under 75 Standardised Mortality Rates (SMR U75)

Primary Health and Adult Community

As in the health promotion and disease prevention PoC, there are no age-gender weights for this PoC. SMR U75 is used to adjust for need as before but is only applied to the population aged 16-64.

Prescribing

Age effect

The age-gender weights for this formula are based upon eight age bands from 0-4 to 75+, they are given in Table 10.

Additional Need

The calculation of the additional needs index is as:

121.967 (Proportion of Babies on the GP List) + 23.937 (Proportion of Dep children in lone parent HH) -0.294 (% Persons 16-74 Students) + 0.2 (Education)

In the original model, the 2005 multiple deprivation education domain was used, however this is not available for England. Following consultation with DMB the proportion of 25-29 year olds with no or low qualifications taken from the 2001 Census was chosen to replace this education domain. The chosen indicator is now a major part of the 2010 updated education domain in Northern Ireland.

GMS

Age effect

The age-gender weights for this PoC are in seven bands from 0-4 to 85+ and are shown in Table 11

Additional need

The calculation of the additional needs index is as follows:

0.195 (Limiting long-standing illness) + 0.271 (Self-Assessed Health “not good”) + 0.049 (Unemployment rate) -0.024 (Single Carer Households)

Age Gender Weights for all PoCs

Table 3 Age-gender weights for Elective Acute Service

Age Band	Males	Females
0 to 4	274.22	221.39
5 to 9	133.96	108.26
10 to 14	102.82	94.49
15 to 19	114.34	96.63
20 to 24	127.66	129.52
25 to 29	110.56	140.67
30 to 34	122.31	187.36
35 to 39	158.58	223.04
40 to 44	191.18	267.39
45 to 49	221.98	310.46
50 to 54	284.77	336.59
55 to 59	394.66	408.36
60 to 64	529.02	479.28
65 to 69	648.77	521.93
70 to 74	799.88	550.9
75 to 79	880.05	650.17
80 to 84	820.72	621.1
85 and over	637.12	451.7

Table 4 Age-gender weights for Non Elective Acute Service

Age Band	Males	Females
0 to 4	235.19	189.26
5 to 9	33.95	27.63
10 to 14	36.02	29.95
15 to 19	51.48	46.86
20 to 24	63.74	62.02
25 to 29	52.47	60.99
30 to 34	54.15	63.56
35 to 39	73.89	65.32
40 to 44	98.99	81.5
45 to 49	116.27	84.05
50 to 54	129.44	106.2
55 to 59	200.96	136.73
60 to 64	260.98	201.51
65 to 69	402.04	267.42
70 to 74	562.06	371.88
75 to 79	778.06	557.75
80 to 84	1006.13	844.67
85 and over	1350.79	1005.38

Table 5 Age Gender weights for the family and child care PoC

Age band	0-4	5-9	10-14	15-19	20-44
Male	1.14	1.36	1.37	1	0.1
Female	1.02	1.25	1.2	1.15	0.1

Table 6 Age Gender weights for the Elderly PoC

Age Band	65-69	70-74	75-79	80-84	85+
Males	299.08	596.3	1239.81	2453.25	4859.86
Females	270.61	652.47	1510.57	3380.58	6708.15

Table 7 Age-gender weights for Mental Health PoC

Age	0-4	5-14	15-44	45-64	65-74	75-84	85+
Male	0.0	0.2	1.0	1.5	1.6	1.6	1.4
Female	0.0	0.2	0.9	1.3	1.6	1.8	2.1

Table 8 Age-gender weights for Learning Disability PoC

Age	0-19	20-34	35-49	50+
Male	23.35	36.21	33.27	19.49
Female	14.33	25.71	27.06	15.86

Table 9 Age-gender weights for Physical and Sensory Disability PoC

Age	0-24	25-44	45-64
Male	7.6	10.4	29.6
Female	6.2	13.1	36.3

Table 10 Age-gender weights for Prescribing

Age	0-4	5-15	16-24	25-44	45-59	60-64	65-74	75+
Males	1.49	1.23	1.11	2.28	5.56	9.91	13.04	16.72
Females	1.25	1	1.52	3.02	6.49	10.1	12.71	16.39

Table 11 Age-gender weights for GMS

Age	0-4	5-15	16-44	45-64	65-74	75-84	85+
Males	2.47	1.00	1.26	2.88	4.58	5.22	7.67
Females	2.41	1.09	3.36	4.27	4.56	6.35	7.36

English allocation models

The English allocation models consist of separate formulae, concerning Hospital and Community Health Service (HCHS) Family Health Services (FHS) and Personal Social Services (PSS). Each of these is slightly different and each is discussed below.

HCHS

HCHS consists of four formulae Acute (67.5%), Maternity (2.9%), Mental health (16.1%) and HIV (1%). In addition to these there are three adjustments the Health inequalities adjustment which is used to allocate funds directly 12.4%); the Emergency Ambulance Cost Adjustment (EACA) and the Market forces factor (MFF) cost adjustment The resultant index for the MFF and EACA adjustments are applied to the overall share of each area.

Acute

The acute formula suite consists of 18 formulae, one for each 5-year age band from 0-4, 5-9 etc up to 80-84 and 85+ each of these formula consists of a number of variables from the table below plus the age specific death rate for each age band.

Table 12 Needs indicators and coefficients included in the acute models

Age Band	0-4	5-9	10-14	15-19	20-24	25-29
Age Specific Death Rate	202.5	541.5	494.5	465.7	883.1	209.5
Standardised No Qualifications	9.5	11.9	6.2			23.6
Young people not staying in education				13.7	20.6	
Standardised limiting long term illness				12.1	14.5	
pension credit claimants						
low birth weight births	5.4					
ID2004: income deprivation affecting children	13.7	10.4				
Disability living allowance claimants under 16			13.0			
New Deal for young people claimants						8.5
Disability living allowance claimants						16.3
Incapacity Benefit/Severe Disability Allowance						
DLA claimants over 60						
Constant	317.6	401.5	378.9	216.0	536.0	328.5

Table 12 Needs indicators and coefficients included in the acute models (continued)

Age Band	**30-34**	**35-39**	**40-44**	**45-49**	**50-54**	**55-59**
Age Specific Death Rate	316.5	344.9	418.0	292.2	285.6	294.1
Standardised No Qualifications	21.5		22.4	27.4	31.0	23.9
Young people not staying in education		7.1				
Standardised limiting long term illness		23.9	27.6	32.3	32.8	42.3
pension credit claimants				18.7	25.1	33.3
low birth weight births						
ID2004: income deprivation affecting children						
DLA claimants under 16						
New Deal for young people claimants	6.5					
DLA claimants	15.9					
Incapacity Benefit/Severe Disability Allowance		24.5	15.7			
DLA claimants over 60						
Constant	378.3	413.8	476.9	492.4	554.0	658.0
Age Band	**60-64**	**65-69**	**70-74**	**75-79**	**80-84**	**85+**
Age Specific Death Rate	173.5	211.9	180.2	148.8	117.5	21.8
Standardised No Qualifications	20.0			38.2	28.4	
Young people not staying in education						
Standardised limiting long term illness	33.5					
pension credit claimants	48.1	65.5	57.5	44.5	33.3	124.1
low birth weight births						
ID2004: income deprivation affecting children						
DLA claimants under 16						
New Deal for young people claimants						
DLA claimants						
Incapacity Benefit/Severe Disability Allowance						
DLA claimants over 60		36.3	62.1			258.2
Constant	818.4	985.2	1211.2	1423.9	1616.5	2705.0

Maternity

The maternity formula has no age specific element to it, instead it is based on a cost per birth approach. Where the average cost is calculated using the mean house price and the proportion of low birth weight births. This average cost is multiplied by the total births recorded and the share of this final pot is taken as the overall share.

This formula is calculated as:

2308.8 + 24.7(proportion of low birth weight births) - 96.06(mean house price)

Mental health

The mental health formula is a two-stage formula with age weights for the same 18 individual age bands as the acute model.

The additional need element of the mental health formula is as:

0.385 + 0.358 (Comparative mortality factor under 65 years) + 0.338 (Proportion aged 60 and over claiming income support) + 0.034 (housing domain) +0.636(psycho-social morbidity index)

HIV

The HIV formula consists of two elements HIV treatment and care and HIV prevention these are combined at 80% and 20% respectively. The treatment and care element depends upon the normalised prevalence of HIV observed in the Survey of Prevalent HIV Infections Diagnosed (SOPHID). The prevention consists of the SOPHID prevalence combined with the crude 15-44 population weighted at a weighting of 60% and 40% respectively.

Health inequalities adjustment

This is based upon the disability free life expectancy (DFLE) for each area, the population of each area is weighted by how many years below 70 its DFLE is. Each area's share of the total weighted population is used as its share of the health inequalities adjustment.

MFF

The MFF for HCHS is made up from the elements shown below

Staff (56.1%)
This is based upon analysis of the annual survey of hours and earnings (ASHE)
Medical and Dental London Weighting (13.8%)
Is based upon the location of the area and amount serving London.
Buildings (3.0%)
Is based upon location factors from Building Cost Information Service
Land (0.6%)
Is calculated based upon the valuation office agency's (VOA) valuation of the estates
Other (26.5%)
This is currently set at 1

EACA
The EACA is based upon the rurality index of the area, the number of urgent and emergency ambulance journeys and the proportion of these journeys, which are emergency.

FHS

FHS consists of two formulae Prescribing and Primary Medial Services (PMS) the adjustments that are applied to each are discussed below.

Prescribing

The prescribing formula is a two stage formula with a set of age gender weights applied to the crude population, with nine age bands ranging from 0-4 to 75+ the weight attributed to each age band increases with age.

The additional need element of this formula is constructed as follows:

0.997 + 0.044 (Percentage Limiting Long-Term Illness) +
0.050 (Disability Living Allowance Claimants) + 0.006 (Low Income Scheme Index) +
0.007 (Proportion of Low Birthweight Births)

The Health inequalities adjustment is also applied as 15% of allocation in this formula

PMS

The PMS formula is a two stage formula with a set of age gender weights applied to the crude population, with seven age bands ranging from 0-4 to 85+ the weight attributed to each age band increases with age.
The additional need element of this formula is constructed as follows:

48.1198 + 0.26115 (Standardised Limiting Long Term Illness) + 0.23676 (Standardised Mortality Rate for the under 65s)

The Health inequalities adjustment is also applied as 15% of allocation in this formula
In addition, there is also a PMS MFF

PMS MFF

The building and other elements of the PMS MFF are the same as the HCHS MFF, practice pay is the same as staff in HCHS. The Land index is based on small site valuations rather than the trust estates. The GP pay index is adapted from the index of deprivation.

Table 13 Elements of PMS MFF

Element	Weight
GP Pay	44.9%
Practice Pay	30.7%
Buildings	5.8%
Land	1.2%
Other	17.5%

PSS

The PSS formula consists of three elements Children's, Younger Adults and Older Adults these are discussed below.

Children's

Children's social care is calculated as the population of 0-17 year old in each area multiplied by the basic amount (28.3003) plus a deprivation top up multiplied by foster care adjustment multiplied be the area cost adjustment for children

The deprivation top up constructed from:

262.56(Children without Good Health) + 148.735(IS/JSA claimants 18-64) + 185.4902 (Children of IS/JSA claimants) + 100.0765 (Children in Black Ethnic Groups) - 29.3071

The foster care adjustment constructed as:

14.8648 (People in other Ethnic Groups) + 34.3436 (People in mixed Ethnic Groups) + 14.0199 (16-74 attained Level 1 or 2) + 6.3347 (16-74 attained Level 4 or 5) + 20.0811 (Females 16-74 looking after home/family)-4.8612

The area cost adjustment calculated to reflect different costs of providing services across the country is based on ASHE data for the areas

Younger adults

Younger adults is constructed from the 18-64 year old population in the area this is multiplied by the basic amount (9.8049) plus the deprivation top up multiplied by an area cost adjustment for younger adults.

The deprivation top up is constructed as:

284.1943 (DLA Recipients 18-64) + 76.8918 (18-64 Long term unemployed) + 26.01(18-64 in Routine/Semi-routine occupations) + 21.7351 (Households with no family) -15.0541

The area cost adjustment is the same as the children's area cost adjustment

Older adults

The older adults formula is based upon over the 65 population of the area this is multiplied by the basic amount of (86.0387) + age Top up + deprivation top up the result of this is multiplied by a low income adjustment then by the sparsity adjustment then by the area cost adjustment for older people.

The age top up is constructed from information on ratio of over 90 year olds to over 65 years old in each area.

The deprivation top up is constructed as:

288.3107 (Older People on AA) +55.7551(Older people in rented acc.)+ 74.6782(Older people living in one person Households) + 224.2339 (Older people on PC/JSA)-77.6613

The low income adjustment is constructed as:

0.1042- 0.102(older people on income support / income based jobseekers allowance / guarantee element of pension credit) + 0.126281166

This is then divided by the area cost adjustment for older people and subtracted from 1

The sparsity adjustment is based upon the population density of the areas in which the over 65s live.

Area cost adjustment for older people is constructed based cost of providing services calculated from ASHE data for the areas

Appendix 2

Table A2:1: Productivity improvement assuming English spending (from 2007/8) applied to Northern Ireland

		2008-9	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2007/2015
HMT NAS +6.02%									
Solid Progress	%	1.2%	-0.5%	6.1%	7.0%	5.0%	5.8%	5.7%	51.2%
Slow Uptake	%	1.7%	-0.5%	6.1%	7.1%	5.3%	5.6%	5.5%	51.9%
Fully Engaged	%	0.9%	-0.7%	5.8%	6.8%	4.8%	5.5%	5.5%	48.8%
Solid Progress	£m	48	-23	286	352	270	325	341	1,600
Slow Uptake	£m	69	-20	290	356	285	317	331	1,628
Fully Engaged	£m	39	-33	274	338	256	308	322	1,504
NI Capitation +11.5%									
Solid Progress	%	1.5%	-0.2%	6.4%	7.3%	5.3%	6.0%	5.9%	53.8%
Slow Uptake	%	2.0%	-0.1%	6.4%	7.4%	5.5%	5.8%	5.7%	54.5%
Fully Engaged	%	1.2%	-0.4%	6.1%	7.1%	5.0%	5.8%	5.7%	51.4%
Solid Progress	£m	61	-9	301	370	283	342	359	1,708
Slow Uptake	£m	83	-6	306	374	299	333	348	1,737
Fully Engaged	£m	52	-19	289	355	268	324	338	1,606
England Capitation +17.2%									
Solid Progress	%	1.8%	0.1%	6.7%	7.6%	6.1%	6.6%	6.6%	56.5%
Slow Uptake	%	2.4%	0.2%	6.7%	7.6%	6.3%	6.4%	6.4%	57.3%
Fully Engaged	%	1.6%	-0.1%	6.4%	7.4%	5.8%	6.4%	6.3%	54.0%
Solid Progress	£m	75	5	318	387	332	383	405	1,905
Slow Uptake	£m	98	8	322	392	349	374	394	1,937
Fully Engaged	£m	65	-5	305	372	316	363	383	1,798
2005 Review judgement +7%									
Solid Progress	%	1.2%	-0.5%	6.1%	7.1%	5.7%	6.2%	6.2%	51.6%
Slow Uptake	%	1.7%	-0.4%	6.2%	7.1%	5.9%	6.0%	6.0%	52.4%
Fully Engaged	%	1.0%	-0.7%	5.9%	6.9%	5.5%	6.0%	6.0%	49.3%
Solid Progress	£m	51	-21	288	355	305	351	371	1,701
Slow Uptake	£m	72	-18	292	360	320	343	361	1,730
Fully Engaged	£m	42	-30	276	341	290	333	351	1,603
2011 Review judgement 9%									
Solid Progress	%	1.3%	-0.4%	6.2%	7.2%	5.8%	6.3%	6.3%	52.6%
Slow Uptake	%	1.8%	-0.3%	6.3%	7.2%	6.0%	6.1%	6.1%	53.3%
Fully Engaged	%	1.1%	-0.6%	6.0%	6.9%	5.5%	6.1%	6.1%	50.2%
Solid Progress	£m	55	-16	294	362	310	357	378	1,741
Slow Uptake	£m	77	-13	298	366	326	349	368	1,770
Fully Engaged	£m	46	-26	282	347	295	339	357	1,641

Appendix 3: Key drivers of overall spending paths in Wanless scenarios

	Solid Progress	Slow Uptake	Fully Engaged
National Service Frameworks - CURRENT	Delivering best practice in the five NSF disease areas - CHD, cancer, renal disease, mental health and diabetes. Extending the NSF approach to other areas of the NHS over the next 20 years. Delivering best practice in these five disease areas represents an average real terms increase approaching 8% a year. These (and new NSFs) are key to the NHS Plan's quality strategy for 'catching up'. Costs are over and above the impact of demographic change, and 'quality' is defined in terms of access, technology and other aspects of service delivery and outcome.		
National Service Frameworks - NEW	Extrapolation of the costs of improvements in existing NSF areas to other specific diseases. To do this, spending may need to increase by 6 to 8% a year in real terms over a period of 10 years. New NSFs are rolled out across other areas in phases, at an average rate of two per year, ensuring complete coverage over the 20 years of the Review. Future NSFs include estimates of the resources necessary for their delivery; be supported by improved information and information collection; and take account of the fact that patients may have co-existing conditions.		
…and medical technology	Contributes around 3 percentage points a year to growth in health spending	Contributes around 2 percentage points a year to growth in health spending	Contributes around 3 percentage points a year to growth in health spending
Fast access - waiting times	Maximum inpatient waiting time: 15 to 6 months (by 2005-06), to 3 months (by 2008-09), to 2 weeks (by 2022-23). Maximum outpatient waiting time (excluding cancer): 6 to 3 months (by 2005-06, maintained to 2008-09), to 2 weeks (by 2022-23). For all three scenarios, the additional cost of reducing waiting times to two weeks is estimated to be around £10 billion a year (2002 prices) by 2022-23.		
Clinical governance	Medical staff in hospitals and primary care move from 5% of time devoted to clinical governance to 10% by 2010-11. Nursing and other professional staff increase clinical governance time from 2% to 10% by 2010-11. Benefits realised after 5 years: (i) 15% reduction in hospital acquired infections (HAI) in acute care by 2012-13 (could lead to fall of 2.8% in all inpatient activity; (ii) 10% reduction in other adverse incidents in acute care by 2012-13 (could lead to an additional 0.6% reduction in inpatient activity; (iii) improvement in avoidable emergency admissions in the worst performing 25 per cent of health Authorities on this measure by 2012-13; (iv) 25% reduction in clinical negligence bill from reduction in number of incidents in obstetrics and gynaecology by 2005. The additional cost of improved clinical governance estimated to be around £1.4 billion a year by 2022-23, with most of this coming through in the first five years.		

Capital: Modernising the NHS estate	Over the next 20 years, one third of NHS hospital estates will be replaced; equipment (excluding ICT) is replaced every eight years; in new hospitals, 75 per cent of beds are in single en-suite rooms and a maximum of four beds per room: the entire primary care estate will be upgraded or replaced over the next 10 years		
…and ICT	Spend doubles in real terms by 2003-04: to 3% of total spend.	Spend doubles in real terms by 2007-08: to 3% of total spend	Spend doubles in real terms by 2003-04: to 3% of total spend
Pay and prices	Total HCHS pay rises by 2.4% a year in real terms (over and above GDP deflator inflation). Price inflation assumed to be 2.5% throughout the 20 year period. Pay in GMS sector assumed to rise by 2.2% a year in real terms. Pay in the PSS sector assumed to rise by 2.3% a year in real terms. Pay and productivity assumptions include Agenda for Change programme covering nurses, GP contract, and the Consultant contract. Pay modernisation assumed to be important in order to increase capacity and create a more flexible workforce with greater scope for team working and facilitating changes in skill mix.		
Workforce	Working Time Directive reduces working hours of hospital doctors to 48 hours a week. Staffing driven by changes in throughput and activity: Average length of stay in hospital falls in line with the estimates in the National Beds Enquiry: Emergency admissions - 7.76 (2000), 7.27 (2005), 6.35 (2010) and 5.43 (2015); Elective admissions - 4.86 (2000), 4.37 (2005), 3.88 (2010) and 3.38 (2015).		
Productivity	Increases from 2 to 2.5% a year in the first decade to 3% a year in the second	Increases from 1.5% a year in the first decade to 1.75% a year in the second	Increases from 2 to 2.5% a year in the first decade to 3% a year in the second
Population health and health seeking behaviour cost drivers			
UK life expectancy at birth	Men 80.0; Women 83.8	Men 78.7; Women 83.0	Men 81.6; Women 85.5
Long-term ill health amongst the elderly	No change in rates of ill health	Increase in long-term ill health (age specific rates of physical dependency increase by 1% a year)	Healthy life expectancy increase broadly in line with life expectancy
Acute ill health among the elderly	5% reduction by 2022	10% increase by 2022	10% reduction by 2022
	Meet current public health targets leading to reductions in hospital admissions and GP visits	No change	Go beyond current public health targets leading to greater reductions in hospital admissions and GP visits, combined with higher spending on health

			promotion
	Health promotion expenditure growing in line with expenditure on GP and hospital care	Health promotion expenditure grows in line with population growth and inflation	Health promotion expenditure growing in line with GP and hospital care, plus an additional £250 million a year by 2007-08 (i.e. a doubling of spend)
Health promotion (smoking, exercise, diet etc)	Less than 24% of adults smoke (Baseline: 27%)	Prevalence of smoking remains the same	Prevalence of smoking achieves solid progress faster before being exceeded
	Less than 15% of pregnant women smoke (Baseline: 18%)	Prevalence of smoking remains the same	Prevalence of smoking achieves solid progress faster before being exceeded
	Number of babies born to teenage mothers in England & Wales reduces to 41,000 in 2005 and to 24,000 by 2010 (Baseline: 48,000)	No change	Number of babies born to teenage mothers achieves the solid progress target faster before being bettered
	5% reduction in births requiring special or intensive care	No change	5% reduction in births requiring special or intensive care
Health promotion (smoking, exercise, diet etc) - continued	Trends in obesity slow and ultimately reverse. From 21% for women, and 17% for men, to 8 and 6%, respectively.	Levels of obesity remain the same	Trends in obesity achieve solid progress aims quicker before being exceeded
	10% reduction in hospital admissions, GP visits and prescriptions related to CHD and stroke for 15-64 year olds. Reductions largely due to reductions in prevalence of smoking, plus higher levels of physical activity and better diet	No change	25% reduction in hospital admissions, GP visits and prescriptions related to CHD and stroke for 15-64 year olds.
	5% reduction in all other hospital admissions, GP visits and prescriptions for 15-64	No change	15% reduction in all other hospital admissions, GP visits and prescriptions for 15-64 year

	year olds. Reductions partly due to reductions in prevalence of smoking, plus higher levels of physical activity and better diet		olds.
Health seeking behaviour among under 65s	By 2022 hospital and GP care use per head amongst over 75s will match current patterns of use among 65-74 year olds	No change in utilisation rates	By 2012 hospital and GP care use per head amongst over 75s will match current patterns of use among 65-74 year olds
	One additional GP visit per person per year on average by 2022	No change	One additional GP visit per person per year on average by 2022
Self-care	Switch of 1% of GP activity to pharmacists; reduction of 17% in outpatient attendances among 225,000 people using self-care	Switch of 1% of GP activity to pharmacists; reduction of 17% in outpatient attendances among 225,000 people using self-care	Switch of 2% of GP activity to pharmacists; reduction of 17% in outpatient attendances among 450,000 people using self-care (has been a step change in public engagement)
	Higher patient expectations	No change	Dramatic improvement in public engagement via ICT
Inequalities	Reduced age discrimination	No change	Successes demonstrated in solid progress are achieved quicker and then are exceeded
	Reduction in socio-economic inequalities in health	Inequalities in health between socio-economic groups of unchanged	Greatest reductions in socio-economic inequalities in health
	Gap in life expectancy between those in the poorest areas and the average falls by at least 10%	No change	Gap in life expectancy in solid progress scenario is achieved quicker before being exceeded
	Smoking amongst adults in manual socio-economic groups falls from 30 to 26% by 2010	No change	Smoking target quickly achieved and exceeded

Appendix 4:

NI HEALTH SERVICE PRODUCTIVITY MEASURE

Introduction

Northern Ireland have been measuring healthcare output since 2002/03 via their Cost Weighted Activity Index (CWAI). This work has been carried out in close liaison with the UK Centre for Measurement of Government Activity (UKCeMGA) and has fed into the UK national accounts (Blue Book). Professor John Appleby, as part of his work for DHSSPS to assess additional budgetary needs for the NI health service, asked that this work was expanded upon to give an estimate of NI productivity.

In order to produce a comprehensive NI estimate of productivity for the healthcare sector, additional analyses is required to produce a robust index of deflated expenditure (or inputs) as well as an assessment of non-tangible quality adjustments. Given the extremely short timeframe allocated for Professor Appleby's project, it was not possible to establish a full set of NI specific deflators and quality adjustments as required, and in some instances, UK adjustments have been applied to NI expenditure and output streams.

Reference years

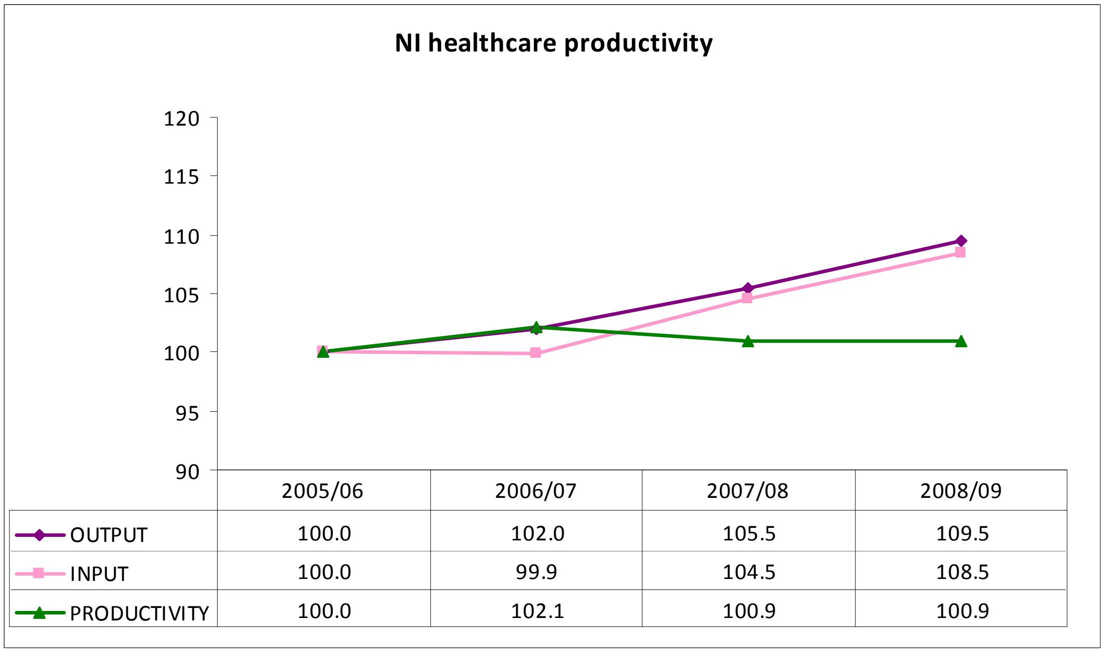
The earliest reliable disaggregated expenditure stream data available for NI related to the 2005/06 financial year while the latest relates to 2008/09. The change in productivity is therefore calculated from 2005/06 to 2008/09. A separate output index is supplied showing change in output from 2003/04 to 2008/09 (the entire NI CWAI series). The output and input data in the NI calculations is based on financial year, which meant that the UKCeMGA data used have been converted from calendar to financial year.

Productivity

The methodology used to calculate productivity in this report is on a similar basis to that outlined in UKCeMGA's most recent productivity report ("Public Service Output, Inputs and Productivity: Healthcare 2010"). Productivity is calculated dividing the change in output by the change in input (see figure 1). The UK productivity for the same time period is set out in Figure 2, although it should be noted that this has will differ from that officially published by UKCeMGA as it has been converted to financial year from a calendar year basis (using a simplified methodology of 75%/25%). While the productivity estimates for the UK and NI were calculated on a similar basis, there are a number of key differences which should be borne in mind when comparing the estimates. The differences in methodology are discussed below.

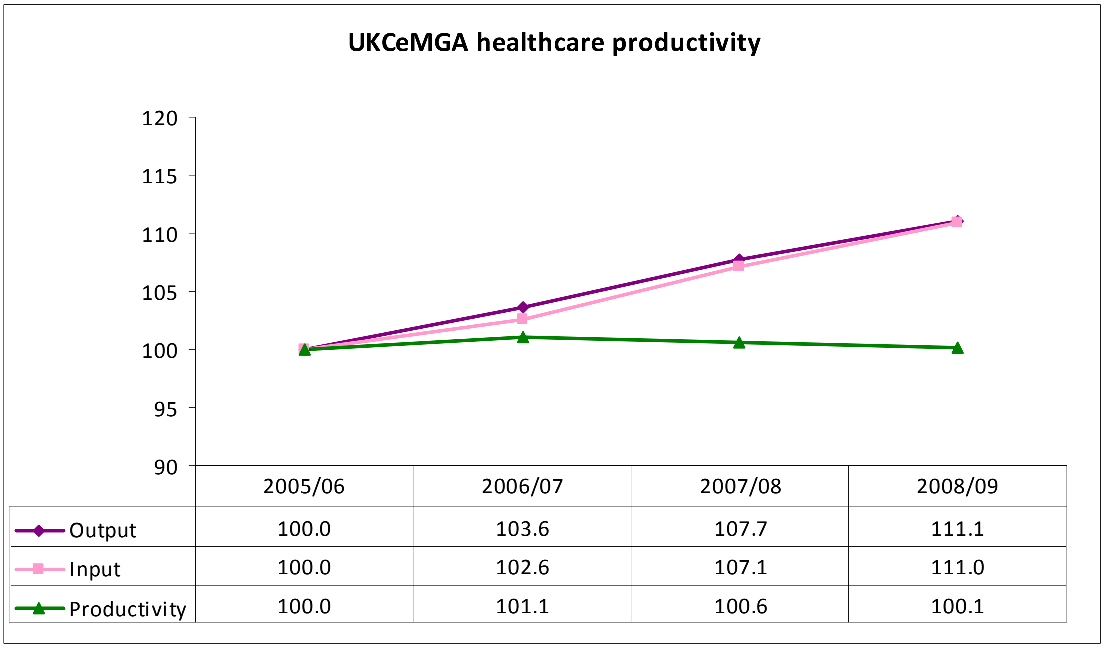
The figures show that productivity within NI has grown by 0.9% in the period 2005/06 - 2008/09. This compares with 0.1% growth in the wider UK. This measure simply reports the relative change in productivity and does not compare absolute productivity levels. It should also be noted that productivity is subject to quite a lot of year-on-year fluctuation and therefore care should be taken in considering changes over such a relatively short time period.

Figure 1



	2005/06	2006/07	2007/08	2008/09
◆ OUTPUT	100.0	102.0	105.5	109.5
■ INPUT	100.0	99.9	104.5	108.5
▲ PRODUCTIVITY	100.0	102.1	100.9	100.9

Figure 2



UKCeMGA healthcare productivity

	2005/06	2006/07	2007/08	2008/09
Output	100.0	103.6	107.7	111.1
Input	100.0	102.6	107.1	111.0
Productivity	100.0	101.1	100.6	100.1

Triangulation

The aim of triangulation is to help users understand productivity estimates by providing additional contextual information, giving a wider picture than is possible in a single measure of healthcare productivity. The figures show that productivity within NI has grown by 0.9% in the period 2005/06 -2008/09 which was supported by some of the evidence set out in the UKCeMGA 2010 article ‘Public Service Output, Inputs and Productivity Healthcare Triangulation’. This included an increase in hospital elective day case rate (as opposed to overnight stay) and a reduction in average length of hospital stay. Both are major drivers in reducing costs and increasing productivity in healthcare services. Although the time frame for the UKCeMGA article was 1995/06 to 2007/08, these broad trends continued into the period covered in this paper.

Output

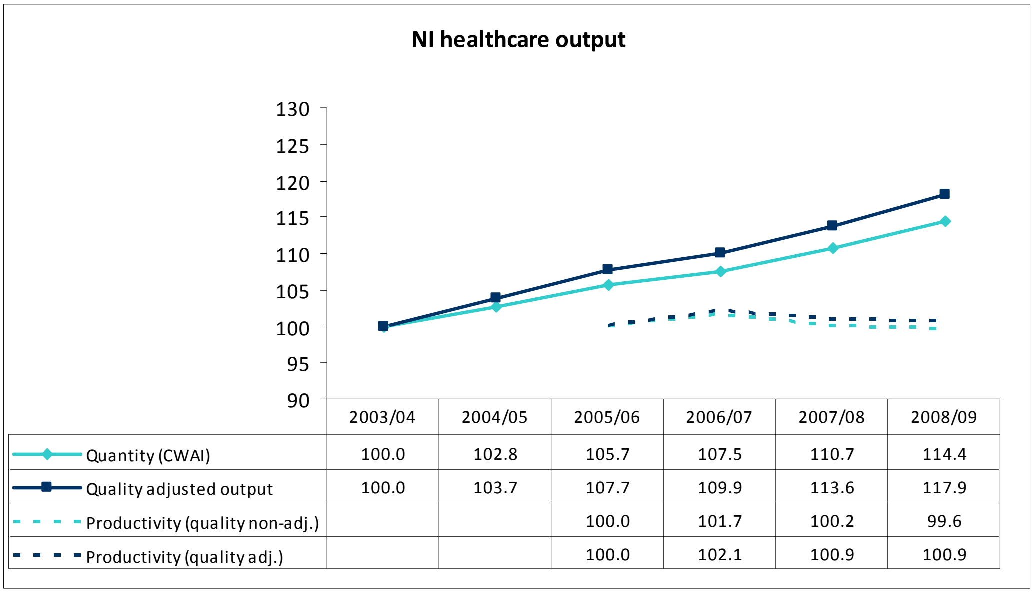
DHSSPS has supplied UKCeMGA with a healthcare output measure (Cost Weighted Activity Index) since 2002/03 which has been included in the UK National Accounts (Blue book). The most up to date notes (2008/09) on the methodology used to calculate CWAI can be found in appendix 1. This output measure does not include Personal Social Services as this is not included in the England healthcare service. The output measure has a coverage in excess of 80%.

Quality adjustments

Output is, by ONS, quality adjusted, using the York Centre for Health Economics method for quality adjustments. NI does not yet have a separate quality measure, and hence, the UK quality measure has been applied to the CWAI figures. The quality adjustments have been converted from calendar year to financial year. It is not known whether the scale of these quality adjustments are wholly appropriate for NI and further work would be needed to produce NI versions of these adjustments. This could not be completed within the relatively short time frame for Professor Appleby's work.

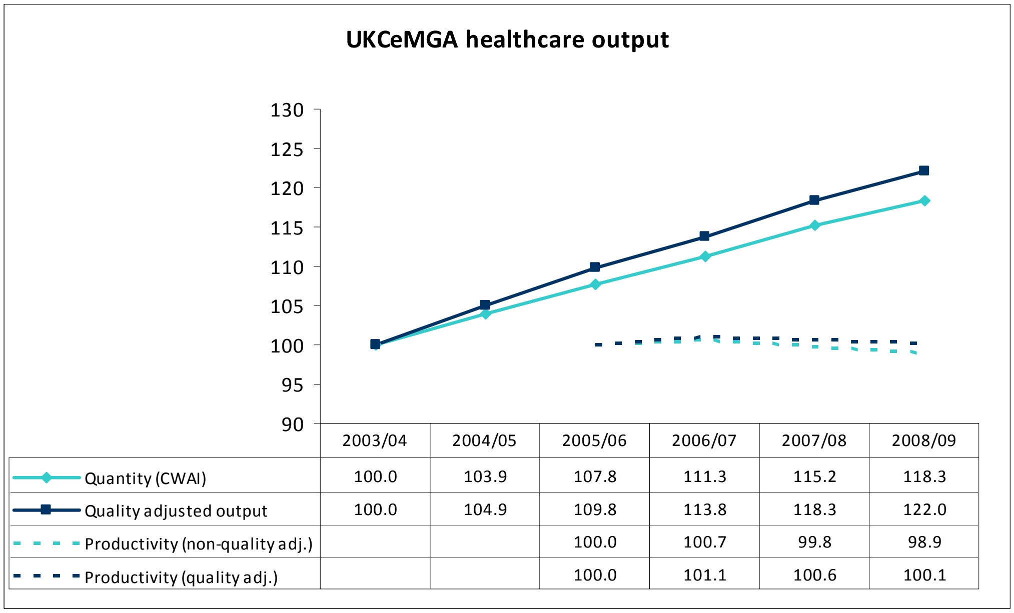
Figure 3 sets out the NI output index, both adjusted and unadjusted for quality. For comparison, figure 4 sets out the UKCeMGA output index, converted to financial year.

Figure 3



	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09
Quantity (CWAI)	100.0	102.8	105.7	107.5	110.7	114.4
Quality adjusted output	100.0	103.7	107.7	109.9	113.6	117.9
Productivity (quality non-adj.)			100.0	101.7	100.2	99.6
Productivity (quality adj.)			100.0	102.1	100.9	100.9

Figure 4


UKCeMGA healthcare output

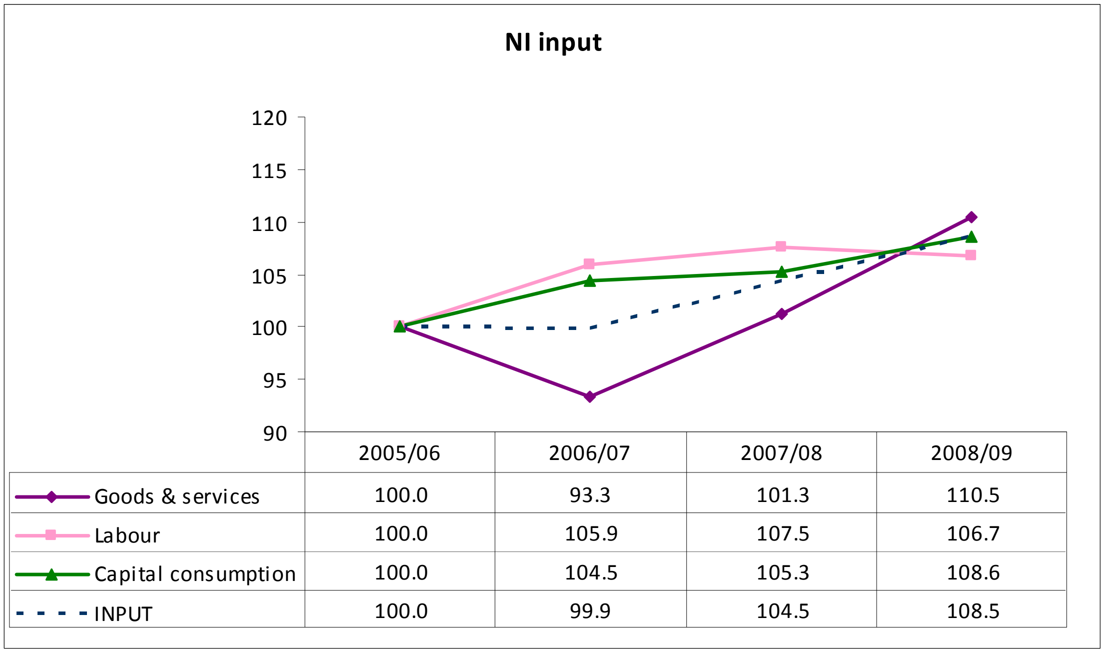
	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09
Quantity (CWAI)	100.0	103.9	107.8	111.3	115.2	118.3
Quality adjusted output	100.0	104.9	109.8	113.8	118.3	122.0
Productivity (non-quality adj.)			100.0	100.7	99.8	98.9
Productivity (quality adj.)			100.0	101.1	100.6	100.1

Input
The NI input index is calculated using expenditure for goods & services, labour and capital consumption. These are weighted according to their total expenditure to form the input index. In the UKCeMGA's UK productivity calculations, the expenditure streams are deflated by a separate deflator for each expenditure stream (table1). As mentioned above (and explained in more detail below) an overall UK deflator has been used for goods & services for the NI productivity measure. Overall there was an increase in healthcare inputs in real terms of 8.5% between 2005/06 and 2008/09.

Table 1

Expenditure category	**Deflator used for UK**	**Deflator used for NI**
HCHS Pay	Pay costs index	Pay costs index
DH Admin: Pay	DH Admin pay costs index	Pay costs index
Purchase of health care from non-NHS bodies	Weighted combination of Pay costs index and Health Services Cost Index	Overall UK deflator for goods & services. Calculated extracting the overall deflation from the UKCeMGA total expenditure on goods & services.
Other HCHS non-pay expenditure	Health Services Cost Index	
General and personal medical services: GPs' own income	GPs' own income deflator	
General and personal medical services: GPs' staff costs	GPs' staff costs deflator	
General and personal medical services: GPs' goods and services	GPs' goods and services deflator	
General and personal dental services: Net expenditure	Dental deflator	
General ophthalmic services gross expenditure	Sight tests deflator	
Pharmaceutical services: total payments to pharmacists	Pharmacists deflator	
Net expenditure on GP prescribed drugs	Drugs deflator	
Welfare food scheme	RPI Food	
EEA costs – not applicable for NI as DH expenditure on this is for the UK	Health Services Costs Index	
Other CHMS	Health Services Costs Index	
DH Admin: Non-pay	Health Services Costs Index	

Figure 5



	2005/06	2006/07	2007/08	2008/09
Goods & services	100.0	93.3	101.3	110.5
Labour	100.0	105.9	107.5	106.7
Capital consumption	100.0	104.5	105.3	108.6
INPUT	100.0	99.9	104.5	108.5

Capital consumption

Capital consumption in the UK productivity measure, produced by UKCeMGA, is calculated for the whole of UK and it is not possible to extract the individual countries figures from the UK figure. As it is not possible to extract the exact NI figure, an identical percentage share of the total UK expenditure (generally around 2% of the total input) was added to the NI labour and goods & services expenditure as NI capital consumption. The UK deflator was applied to NI capital consumption, fig 5 shows that deflated capital consumption increased by 8.6% over the period.

Goods & services

Goods & services constitutes a range of expenditure streams, namely Hospital & Community Health Services (DHSSPS and non-DHSSPS activity), General Medical Practitioner services, General Dental Services, General Ophthalmic Services, Pharmaceutical services, Prescription Drugs, Central Health & Miscellaneous Services and the Department's admin expenditure. These expenditure streams are deflated to remove the effect of inflation. The expenditure streams have been extracted from the Final Outturn figures prepared by DHSSPS and submitted to Central Expenditure Division in the Department of Finance and Personnel. These figures are used to inform the final outturn reported in the final accounts of all entities within the DHSSPS budgeting boundary. Totals used reflect Outturn for Departmental Expenditure Limit (Admin and Other Resource) and exclude NI Fire and Rescue Service, Superannuation, Personal Social Services, Capital Expenditure, Annually Managed Expenditure, Depreciation and Impairment expenditure.

Goods & Services deflator

Due to time constraints, the overall deflator for UK goods and services, calculated by ONS for the UK health productivity measure, was applied to deflate the Northern Ireland expenditure on goods & services. In doing this we have made two assumptions. Firstly, that price changes in the goods and services bought to produce healthcare in Northern Ireland are the same as price changes in the goods and services bought to produce healthcare in the UK (in practice England) as a whole. Secondly, that the same kinds of items are bought in Northern Ireland as in England and in the same proportions. Although calculation and applying of local deflators would be the preferred method, as this was not possible, given the available time, using the UK deflator would seem to be reasonable.

Hospital and Community Health Services (HCHS)

HCHS is calculated excluding Personal Social Services (PSS) from both pay and non-pay as PSS is not included in the output measure.

Hospital and Community Health Services - Non-DHSSPS activities

Non-DHSSPS activities are goods & services purchased from non-DHSSPS bodies. These activities are split from the general hospital & community health services expenditure stream as a specific deflator is applied to it in the UKCeMGA input calculations (table 1). There was however difficulty extracting this expenditure stream for NI. Although the expenditure from the Final Outturn fall into bodies that are within the DHSSPS budgeting boundaries, the Department does not in itself purchase the services being provided by the HSCB etc, but only allocates the funding to do so. Therefore, this source of expenditure does not contain any details on what services may have been provided by non-DHSSPS bodies to those organisations that DHSSPS funds. As no separate NI deflator was to be applied to the non-DHSSPS activities in this NI exercise (the same deflator applied to all goods & services expenditure streams), it was not considered necessary to pursue a separate non-DHSSPS activities expenditure stream for NI, although it may pose problems when this work is updated in the future with specific NI information.

GP services

The blue book includes GP services as part of the goods & services expenditure, however the UKCeMGA calculation of productivity remove salaries to GP's and GP staff from goods & services and include this to the labour element of input. However, in NI, the General Medical Services cannot be spilt to differentiate between GP salary, staff salaries and other expenses (per GMS Branch). This because GPs have a contract for service as opposed to a salary and staff costs in a practice would be included within its expenses. As it is not possible to extract these elements from the total expenditure for Northern Ireland, all GP services (including GP pay) are included in goods & services.

General dental services

Expenditure on general dental services is the gross expenditure less receipts.

General ophthalmic services

Expenditure on general ophthalmic services is the gross expenditure.

Pharmaceutical services & Prescription drugs

According to the UKCeMGA calculations, the pharmaceutical implicit payments are added to the gross expenditure and then deflated with the appropriate pharmaceutical services deflator to create the pharmaceutical services index. The implicit payments together with receipts payments are then removed from the FHS Drugs expenditure and this total deflated with its appropriate drugs deflator. However, as the same deflator is used on all expenditure streams for NI, it has little effect on the results of this exercise.

Central Health & Miscellaneous Services (CHMS)

This expenditure stream includes welfare foods (e.g. Healthy Start programme) and other CHMS expenditures.

Department's administrative expenditure

This expenditure includes administrative cash and non-cash costs.

Labour

With the exception of 2005/06, labour accounted for the largest proportion of the total expenditure (average of 51%). The labour index (pay cost index) is calculated using a so called direct measure by calculating a Laspeyres index based on the average salary for different labour categories and the number of full time equivalent staff for the same categories.

It was not possible to get the labour WTE and salaries from the same source for the whole period. The 2005/06 - 2007/08 data were taken from the Payroll Extract (source: BSO ITS) and 2008/09 derived from payscales and paypoints held in Human Resource & Management System (HRMS). In order to make a consistent comparison, staff figures for the whole period were forced to total the annual HRMS staff figures, using the staff weights from the original source where it was not possible to make a direct conversion.

Conclusion

The methodology used to produce productivity estimates for NI is reasonable, given the limited time available. However it should be borne in mind that the results will be subject to a degree of revision once NI specific deflators and quality adjustments are calculated. As with the UKCeMGA calculation, the resultant figures produced from this exercise are not a complete picture of healthcare productivity and other information such as the triangulation information discussed earlier should also be considered. For instance workforce productivity figures produced by DHSSPS show persistently lower productivity figures for NI compared with England. Also, as the UKCeMGA productivity estimates produced for the UK over a longer period show a degree of year-on-year volatility, the question of considering the robustness of figures produced for a three-year period should be borne in mind when comparing against the overall UK figure.

This has been a very useful project and should mark the start of further investigative work and analyses to establish an ongoing estimate of productivity of the healthcare sector in NI.

18th February 2011
Project Support Analysis Branch – DHSSPS

Annex to Appendix 4:

NORTHERN IRELAND HEALTH COST WEIGHTED ACTIVITY INDEX (CWAI): 2008/09

Introduction

This index has been developed in response to the Atkinson Review recommendation that published UK output measures should be improved, where possible, via the incorporation of data from all four constituent countries. It will also form the basis of a future NI productivity/efficiency measure.

The model replicates, as far as possible given current data constraints, the DoH methodology that was first introduced in the 2004 UK national accounts. Although the main activity categories have been covered in respect of hospital, community and family health services, NI does not provide certain services which are available in England, e.g., NHS direct, Walk-in centres, etc. As with the English version, the model calculates a cost weighted average of all covered activity in each financial year and also calculates the overall percentage increase/decrease in cost weighted activity each year. The previous year's unit costs have been applied to both years' activity data which corresponds to the Laspeyres method although sufficient information is available within the model to calculate the index according to other methodologies such as the Paasche and Fisher methods.

Specific model notes: 2008/09

The 2008/09 NI CWAI essentially employs the same methodology as that used in previous years.

Inpatients

All of the inpatient HRG activity data is quality assured using information from the NI Hospital Episode Records System, which is regarded as being of excellent quality and is supplied with electronic downloads directly from hospital administration systems.

Activity on the whole has increased over the year, as it has in previous years. This has occurred across a number of HRGs/specialties and can be attributed largely to the target of treating patients within 4 hours of arrival at A&E. This means that a large volume of patients arriving at A&E are referred on to specialists (and therefore admitted) even if for a short time only before they are discharged.

As for last year's CWAI, unbundled HRGs have been included in their own section. Other activity is grouped into elective (including daycases) and non-elective sections also as in previous CWAIs. The non-specialist mental health HRGs (WD codes) are compared by HRG by specialty. There have been some issues with changes in the current version of HRG v4.0 with some unbundled HRGs 'rebundled' into their parent HRG. This is the case for all the RA and RB codes, which due to no recorded unbundled activity in 2008/09 had a negative effect on the overall CWAI (around -0.6 percentage points).

There are some coding issues where the 2007/08 HRG codes have been removed for 2008/09. For most indictors this is due to the HRG codes having changed to include length of stay or age of the patient. As a result, one HRG code sees a major loss in activity (a code that is not used in 2008/09) while another related HRG code sees a large increase (where this activity is mapped to in 2008/09). In these instances a grouped indicator was created. In total 75 grouped indicators were created for Elective inpatients (including day cases) and 64 for Non-Elective inpatients. In the CWAI spreadsheet the HRG codes that are grouped are marked bold and the group indicator is highlighted light blue. (An overview of the grouped HRG codes is attached in appendix A.)

There was an issue with changes in the root mapping of the patients treatments in 2008/09 compared to 2007/08, especially for the FZ codes. This caused, for example, HRG FZ03A, who had an activity of 3 in 2007/08, to increase to 22,145 in 2008/09. Similarly, FZ26A (Endoscopic or Intermediate Large Intestine Procedures 19 years and over), FZ03A (Diagnostic and intermediate procedures on the upper GI tract 19 years and over), HA99Z (Other Procedures for Trauma), FZ34C (Large Intestinal Disorders without CC) and FZ35C (General Abdominal Disorders without CC) all experienced major shifts in activity.

As a result of this issue we were not able to compare activity and cost in 2007/08 and 2008/09 on a like-for-like basis. We could not map costs for 2007/08 to the same configuration as the new mapper and the NHS Information Centre were not able to advise as to how to overcome this problem. We finally settled on grouping ‘Endoscopic Procedures Grouped’, which contained 17 HRG codes (see appendix A), including one of the single high indicators, FZ26A.

By having to group a large number of HRG categories together we are essentially depressing the overall Index. We cannot be certain as to how much we are removing an effect caused by changes to the HRG grouper or depressing real growth by grouping the categories together. It was however assumed that the grouping detailed above was a reasonable compromise.

As in previous years, assisted delivery figures have increased across NI and are the highest rates in the UK

Outpatients

NI does not have Outpatient HRG reference cost data so instead has to rely on specialty costs. Not all listed specialties included in the English model are relevant in Northern Ireland and have been zeroed. In addition, some NI-specific specialties have been included.

A&E attendances are not shown separately in the NI model but are captured within the A&E outpatient specialty (both activity and unit cost). A separate A&E attendance unit cost is not available.

General Medicine activity in the Northern Trust increased by 43% and Obstetric attendances went up by 29% in the Southern Trust which contributed to the overall increase for these indicators.

Mental Health/Learning Disability

Generally, there has been a continuous decline in admissions to mental health hospitals which is line with key Government PSA targets to reduce both admissions to and long stays at these hospitals by 10% by 2011. The Bamford review (of mental health and learning disability) recommended that community service is strengthened to progress the resettlement of long-stay patients. However, for 'Mental Illness – Rehabilitation', Belfast City Hospital and Bluestone Hospital are reporting an increase in activity and the South Eastern Trust have an increase in Consultant sessions and Locum costs. The overall running cost at Lakeview hospital in the Western Trust has increased, causing an increase in cost for 'Learning Difficulty - Adult Long Stay'.

The decline in activity for 'Old Age Psychiatry' is partly attributed to a retraction of services in St Luke's hospital. However 'Old Age Psychiatry' has also seen an increase in cost. This is due to all specialties within the Tyrone and Fermanagh hospital site being allocated additional costs and overheads from the hospital main building. Also Belfast Trust saw an increase in cost due to pay and price increases at Knockbracken Healthcare Practice, in addition to better identification of overhead costs.

Physical and Sensory Disability

Altnagelvin Hospital has reported expenditure and activity against 'adults' in 07/08 but it has been reported against 'children' in 0809. We have therefore grouped adult and children activity for Physical and Sensory Disability.

Critical Care

Critical care within Coronary Care Units has seen an increase in 2008/09. This is due to an increase in activity in the Belfast Trust and rising nursing costs and purchasing of medical equipment in Daisy Hill Hospital in the Southern Trust. Recruitment of new consultants in the Northern Trust also added to the increase.

It should be noted that although demand for critical care in NI will tend to fluctuate more year-on-year than in England (due to its small geographic area), the overall level of cover in NI has to be maintained.

Pathology

There are no issues with this data, NI pathology figures (as in England) are based on 'Direct Access' activity only.

Chemotherapy

There are no NI HRG costs or activity information available.

Renal Dialysis

Only hospital-based data are available for this category.

Bone Marrow Transplant

Data on bone marrow transplants are already included in inpatient reference costs.

Spinal Injuries

This is included in the English index below HRG level. In NI, this information is not available at such a detailed level.

Community Services

The increase in District Nursing is partly due to improved data collection (previously estimated and now full year information is available). In the Northern and the Western Trusts 'Specialist Nursing' now also includes more teams of nursing including among others a respiratory team, stoma, rapid response and community stroke team. In the Southern Trust there have been investments in Marie Curie services.

Both the Northern and the Southern Trusts have improved their methodology to split acute and community care activity and cost. This has caused an increase in 'Occupational Therapy – FTF Contacts' activity and cost this year. The Northern and Western Trusts have also had additional investments in Community Mental Health Teams, which contributed to the increased cost.

Rehabilitation

The decrease in activity for 'Rehabilitation bed days - Elderly' is down to a large decrease in activity at Greenpark Hospital in Belfast Trust.

Emergency Ambulance Journeys

It should be noted that as there is a single provider for all NI (Northern Ireland Ambulance Service), it means that productivity depends on demand (as demands will always be met), with local demand in small areas creating greater year on year fluctuations than present in England.

FHS – Prescribing

Although the number of prescriptions for Lipid Regulating Drugs continues to increase, there are in general no data concerns. Based on DoH advice, unit costs are used before discount has been applied. An adjustment (based on aggregated data) has been made to costs in both years to take account of estimated public contributions. Prescribing information is still compared at BNF section level. It is currently not possible to follow the proposed new methodology (using more detailed GenProp coding level) in NI.

FHS – General Dental Services

There are no data concerns. The category excludes private activity and unit costs are net of receipts. FHS dental activity has the last years decreased due to NHS dentists taking on more private work at the expense of NHS work. There has however been an increase in activity in 2008/09, but numbers are not back up to 2006/07 level.

FHS – General Ophthalmic Services

There are no data concerns. The category excludes private activity.

FHS GP Consultations

NI continues to be reliant on the Continuous Household Survey (in conjunction with population mid-year estimates) as the source of its consultation data. Due to smaller NI sample size, a three-year moving average is taken in order to increase the reliability of the estimate. Whilst nurse consultations can be separately estimated, if required, no other breakdown of consultation type is possible. The unit cost is based on the full cost of General Medical Services and it is not possible to obtain a separate unit cost for nurse consultations. The unit cost will therefore represent an average of all consultation types.

England and Scotland have moved to direct capture of consultations data from GP systems. If funding can be secured, it is hoped that the General Medical Services Information System project, after being successfully piloted, will be progressed and that it will be operational and providing reliable data within two to three years for NI.

Quality Assurance

Three main activities make up the bulk of quality assurance conducted on the data used in the Northern Ireland CWAI:

a) checks for consistency of use of HRG activity, and coding between 2007/08 and 2008/09;
b) checks for significant changes in activity between 2007/08 and 2008/09; and
c) checks for significant changes in unit costs between 2007/08 and 2008/09.

Any discrepancies uncovered in the data were investigated with the data being either corrected where an error had been discovered or retained in the event that a satisfactory explanation was put forward by those who originally supplied the information. Any changes that affected previous year’s figures were applied to update all the indices affected.

Coverage

The overall coverage has not yet been calculated for this year’s CWAI (but will be forwarded as soon as complete). It is however expected to be in excess of the 80% coverage which was achieved in 2007/08.

When calculating coverage, it should be noted that Personal Social Services expenditure is excluded and that excess bed-day costs, which are quite significant, are included in the total expenditure denominator. As these do not count toward productivity, and never will, a case could be made for their exclusion.

Results

The Laspeyres index number is used for the CWAI as most of the information feeding into the national accounts does not have reliable cost information for the latest period. The results are shown by activity category in Table 1 overleaf.

Table 1: NI Health Cost Weighted Activity Index by Category (Laspeyres)

	2007/08	**2008/09**
Overall Health CWAI	**3.0%**	**3.3%**
Elective Inpatient Episodes	2.2%	7.1%
Non- Elective Inpatient Episodes	6.3%	7.4%
Unbundled HRGs	14.0%	-52.8%
Outpatient Attendances	2.6%	3.1%
Mental Health/Learning Disability	-8.3%	-3.3%
Physical & Sensory Disability	98.3%	-1.0%
Critical Care	-3.6%	2.0%
Pathology	3.8%	13.0%
Renal Dialysis	7.9%	3.9%
Community Services	-2.4%	4.0%
Rehabilitation	37.4%	-18.3%
Emergency Ambulance Services	8.1%	4.8%
FHS – Prescribing	6.7%	3.8%
FHS – General Dental Services	-7.0%	3.8%
FHS – General Ophthalmic Services	4.8%	4.8%
FHS – General Medical Services	1.6%	-0.4%

16th April 2010
Project Support Analysis Branch – DHSSPS

Northern Ireland
Assembly

COMMITTEE FOR HEALTH, SOCIAL SERVICES AND PUBLIC SAFETY

OFFICIAL REPORT
(Hansard)

‘Transforming Your Care: A Review of Health and Social Care in Northern Ireland’

14 December 2011

NORTHERN IRELAND ASSEMBLY

COMMITTEE FOR HEALTH, SOCIAL SERVICES AND PUBLIC SAFETY

'Transforming Your Care: A Review of Health and Social Care in Northern Ireland'

14 December 2011

Members present for all or part of the proceedings:
Ms Michelle Gildernew (Chairperson)
Mr Jim Wells (Deputy Chairperson)
Ms Paula Bradley
Mr Mickey Brady
Mr Gordon Dunne
Mr Mark H Durkan
Mr Sam Gardiner
Ms Pam Lewis
Mr John McCallister
Mr Kieran McCarthy

Witnesses:

Mr Edwin Poots	) Minister of Health, Social Services and Public Safety
Dr Andrew McCormick	) Department of Health, Social Services and Public Safety
Mr John Compton	) Health and Social Care Review Team

The Chairperson:

I welcome the Minister of Health, Social Services and Public Safety, Edwin Poots, Dr Andrew McCormick, the permanent secretary of the Department of Health, Social Services and Public

Safety (DHSSPS), and Mr John Compton, the chief executive of the Health and Social Care Board. I advise members that the Minister has indicated that he is available for only an hour. We will try our best to let him away at 2.30 pm. I remind members to keep their questions short, please. I hope that we can get everybody in.

Minister, you are very welcome. You are going to give us a short presentation.

Mr Poots (The Minister of Health, Social Services and Public Safety): I thank the Chair and the Committee for the invitation to attend today. Members have had the ‘Transforming Your Care’ report for more than 24 hours, so you have had an opportunity to have a good read of it. We intend to bring a take-note debate to the House in the new year to allow Members outside the Committee for Health, Social Services and Public Safety, and indeed members of the Committee, to engage further in what I believe is an important process. Good engagement will lead to better outputs.

I made my statement in the House yesterday and explained the importance attached to the review. It sets out a compelling case for change and is built on statistical evidence and research, inputs from extensive engagement with stakeholders and a case that has been endorsed by the panel of independent experts.

The review sets out 11 reasons for change and 12 principles for change. Few could disagree with the reasons and principles. They might not always like the outcomes, but our aim is to improve patient care and deliver better outcomes so we need to ensure that patients are treated in the right place at the right time by the right people and reduce over-reliance on hospital care.

If we want to deliver the best outcomes for everyone and to maintain the highest levels of quality and safety in service provision, under the principle of health services being free at the point of need, our full range of health and social care services are unsustainable in their present form. The review proposals represent a radical change to the way our health and social care services are delivered. That change is long overdue.

The review presents proposals for a future model for integrated health and social care. The proposed model, which has been endorsed by the expert panel, is sustainable and should deliver a different, improved and safe service. The model puts individuals, not institutions, at the centre and supports individuals to care for themselves and make good health choices. Health professionals could work together to plan and deliver those services in a much more integrated way, and integrated care partnerships would be set up to join together the full range of health and social care services in their area.

There would be a significant shift from provision of services in hospitals to service in the community, in GP surgeries and closer to home, where it is safe and effective to do that. Services would regard home as the hub and be able to ensure that people can be cared for at home, including at the end of life.

It was perhaps inevitable that much of yesterday’s coverage would be about hospital provision, although, as I outlined, the review is about much more than acute care. Indeed, it covers nine other service areas that deserve equal attention. The report is not prescriptive about the number of hospitals; instead, it sets out services that should be available, including services that acute hospitals must be able to provide. The watchwords are: “safe, resilient and sustainable hospitals”.

The review anticipates that there will be changes at all hospital sites over a five-year period, with the final functionality based on population needs and the principles and criteria set out in the report. Engagement at local level with local commissioning groups (LCGs) and trusts will inform the services to be provided in each area. The key test for any future service configuration has to be sustainability and resilience in clinical terms.

As I said, the review is about much more than hospitals and contains an assessment of the current position and proposals across a number of key service areas, including provision for older people and those with long-term conditions; improving services for those with physical or learning disabilities; provision for people using mental health services; provision for maternity and child health services; palliative and end-of-life care; and for family and childcare.

The report presents a total of 99 proposals. The proposed changes would require the development of different skills and capacities. Workforce planning and development is, and will be, a critical building block in ensuring that staff are appropriately trained and confident in their roles for the model of care.

With regard to services for older people, concerns were raised yesterday about the closure of residential homes. I should make it clear that residential care places have been declining, and a shift of resources from residential care to home care is in line with providing greater independence for people at home and introducing new models such as respite care. We need to move our focus from institutions to individuals.

A change in the model of delivery means that there will be a shift in care from hospital settings to the community. There will also be a shift in resources as funds are reallocated in line with service delivery. It is envisaged that by 2014-15, there will be a shift in funding of around 5% or £83 million from the hospital service budget to other services. The review recommends that transitional funding of around £70 million be provided over the next three years to enable the new model of service to be implemented. I recognise the need for some resources to help to support the shift required.

The review team has produced a wide-ranging set of proposals, and in the coming weeks and months, they will need to be translated into more detailed implementation and stakeholder engagement plans, setting out specific changes to be taken forward. The plans will be based on population plans for each area, drawn up by each of the local commissioning groups with the health and social care trusts. The review recommends that plans are drawn up and published by June 2012 and sets a five-year horizon for changing the provision of services. It is inevitable that changes will need to happen at different timescales, reflecting the current position for specific services in localities but all within a coherent framework provided by the review. I also want effective governance arrangements in place for implementation where the review is one of several key strands of work that need to be progressed in a joined-up way. My Department will put in place programme management structures to take those strands forward to ensure an effective whole-system approach to reforming our health and social care system.

We are very happy to take questions. I suspect that John will probably field a lot of them if they are about the detail of the report. Questions about implementation will probably be answered by Andrew or me.

The Chairperson:

Thanks, Minister. Everybody is on the ball today and nearly all members have indicated that they want to ask questions.

We gave the report a fairly guarded welcome yesterday, before getting into its detail. The longer I had it and the more I hoked through it, the more questions I had. There are certainly some very good things in the report; we accept and acknowledge that.

On the focus on preventative care, proposal 35 states:

> “Preventative screening programmes fully in place to ensure the safest possible outcome to pregnancy.”

Is that a hint towards group B streptococcus screening?

Mr Poots:

I will ask John to answer that.

Mr John Compton (Health and Social Care Review Team):

Whatever the professional advice is, we will respond to it. If professional advice indicates that a certain form of screening should be introduced, we would obviously move towards its introduction. In the report, we were quite keen to recognise the fact that our prevention and screening programmes, and immunisation, are critical in preventing people becoming unwell. We should be really rigorous in making sure that we follow the best professional advice so that Northern Ireland has full implementation of those issues. There is an ongoing debate about the specific screening that you raised. Our judgements will be determined by the professional advice that comes to us.

The Chairperson:

It is the professional advice that worries me, John, given what we have heard in this Committee.

I do not want to spend any time on that today, but I thought that that was interesting.

I also want to mention human papilloma virus (HPV) screening. I did not notice where that is in the report, but I presume that there will be a wider emphasis on it.

Mr Compton:
It is in there.

The Chairperson:
I am delighted that kinship care got a mention. We will come back to that issue in the new year. I was also glad to see a focus on child and adolescent mental health services (CAMHS). We welcome the report’s comments on prevention, primary care and community care. I probably do not speak on behalf of the entire Committee, but I welcome the move towards greater integration and all-Ireland working around the sustainability of services.

Yesterday, the media picked up on the issue of residential homes. It would be interesting to get a bit of clarification on that. I think that I saw the word “substantial” used, but I did not see that all state-owned residential homes were closing. Perhaps you can put some meat on the bones of that. I know that it is a phased five-year strategy, but there needs to be recognition — we talked about this earlier in the week — of the people who perhaps do not have a home to go to and who cannot be accommodated elsewhere, for whom a residential home is their home. There are different reasons why such people should be kept in residential homes, and I hope that there will not be a one-size-fits-all approach to the issue.

I am most interested in the framework for the future — the “roadmap” — to develop the population plan, led by local commissioning groups and supported by health and social care trusts, integrated care partnerships and communities. That is great stuff, but I then find that they are at the bottom rung of the ladder and that that has to be approved by the NI clinical forum, the local commissioning groups, NIMDTA and the Ambulance Service. That then goes up to the Health and Social Care Board for final sign-off. My point — you may have heard it in the media last night — is that a local commissioning group and a local trust could come up with a solution that fits their population size, needs and desires and ticks all the boxes. However, there are two stages at which that plan could be vetoed. Who exactly will be on the clinical forum and how will that veto work?

Mr Compton:

I will deal with the residential care question first. It is a five-year strategy. The number of people applying for and using residential care has been flatlining or declining in the past number of years. At present, we provide care at home, in residential care and in nursing homes, and care for people with dementia. There has been a change in residential care. A number of residential care facilities now provide respite care alongside, if you like, permanent residency and placements. We expect the number of people requiring such a permanent solution to decline, so we envisage a major change in the residential home infrastructure and what it is used for. The need for respite care and such services is indicated in the report, so it is entirely possible that some of those buildings could be converted, for example, into respite centres.

Given that housing associations have services such as housing-with-care, the actual need for residential care is generally declining. The report reflects that decline and considers how we would invest that money, principally into home care. Nothing dramatic has been planned; no one is going to say to old people who are residents that they must pack their bags because it is time to go. It will happen over a five-year period, and there will be a proper evolution, transfer and change in how residential care is provided in the community.

When people are clear about the definitions of home care, nursing home care and dementia and residential care, I do not think that there will be as much opposition as people expect. Often, people confuse residential and nursing home care as being one and the same thing; they are quite distinct services, and there is a strong emphasis on supporting and improving the nursing home care arrangements at the same time. That is the logic and rationale behind the thinking. By saying that home is the hub and that the principle is to support people at home, individuals entering residential care should, by and large, be able to be avoided. We do not say that that would apply to everybody, but it would apply to the majority. That is what we think about the model development.

The point that you raised about the hospital issue is really a “what and how” argument. It is important to clarify that. It is not that someone will set an unreasonable test, if that is what is behind the question. It is not that people will come up with a solution and then be set an unreasonable test. Chris Ham and other members of the panel were very strong about the issue. If, from a review point of view, it is specified that one hospital will do one thing and another hospital will do another, all sorts of difficulties will be created. Solutions need to be built from a local area and a local perspective. However, they need to be built on the basis of clinical evidence on the best outcome and what is known about resilience, sustainability and making hospital services safe. I would not expect a sensible plan from a local commissioning group to disregard those matters, so I do not think that there would be any real difficulty or problem in running through other perspectives to get to a solution. Everybody is working off the same platform of evidence, and there is a real need to have that debate locally with individuals. The issue is a population's need.

The report states that we start with a population's need, and we used the five populations as a way to handle that. We have to consider the best way to organise major acute services for that population. We have to take account of clinical evidence, resilience and sustainability and how to maintain the service safely over a protracted period of time. Everyone knows about our experience over the past two to five years, when that was not the case. We have had crisis situations because we could not recruit doctors or depended on locums, so people had to be transferred. It is good to have a local bottom-up approach to planning and agreement.

The clinical forum is not a veto concept. It is difficult to describe it in an organigram, but it is meant to ensure that clinicians have an absolute say in how services are shaped. The outcome will be much more successful if clinicians have that engagement and have their say. My experience during the review was that there was a strong plea to re-engage clinicians in influencing decision-making. It is not about doctors thinking that there is a right way to do things and disagreeing with a community or local organisation; it is about people working together to provide solutions.

On the other hand, we took the view that it was unreasonable for us to say that everything could remain as is. Quite patently, it cannot, so we indicated that in our judgement. However, our judgement was made at one point in time, and that will be tested as we go through the detail.

Our judgement is that Northern Ireland will have about five to seven major acute networks of service. That is quite an important signal to send out about the likely outcome. We are not specific; populations will look at the issue and bring forward responsible solutions.

The Chairperson:

I will let Sam in because he has to leave soon. I ask for questions and answers to be succinct. I will do a Willie Hay: answers need to be a bit shorter.

Mr Gardiner:

I thank the Minister for his presentation. My question is for John. Proposal 62 states:

> "Close long stay institutions and complete resettlement by 2015."

How many long-stay institutions do we have in Northern Ireland?

Mr Compton:

I think that there are six at the moment.

Mr Gardiner:

Would all those residents —

Mr Compton:

That is the idea. As members will know, we are already in the middle of the implementation of the Bamford review, and it has that timescale. We are reinforcing the timescale for the closure of those institutions. We are well on the way to doing that. The review suggests a transfer of money from acute services to that area to make sure that the target date is delivered.

Mr Gardiner:

The families have not yet been consulted.

Mr Compton:

No. As you will appreciate, many individuals in that situation have very little family support or membership. In such cases, there will be advocacy to make sure that nothing untoward is done. Someone will act on behalf of those people.

Mr Gardiner:

Do you have everything that you asked for out of this report?

Mr Compton:

The report is written exactly as the review panel determined. There was no pressure on us to remove anything or not to include something. It is as it is; it is entirely as the review team wanted it.

Mr Gardiner:

Are there things that you would have liked to achieve that you have not achieved as a result of the report?

Mr Compton:

No.

Mr Gardiner:

Are you satisfied with it?

Mr Compton:

I am absolutely satisfied that the review team put together the report as it is written. No one applied editorial sanction to it outside the process. I will be quite straightforward: I assure you that the independent review people would not have tolerated that.

Mr Gardiner:

As the saying goes, we will watch this space.

Mr Poots:

I will clarify. John updated me every two weeks on the report and the emerging issues. During our engagements, I made it absolutely clear that I had asked a panel of experts to give us advice.

I could accept all the report, parts of the report or none of it. However, I asked the panel of experts to draw up advice and pass it on to me. I had to respect the integrity of the people who were asked to do that work. It is not an independent report as such, but it was conducted independently. No political influence was brought to bear, even concerning some of the more difficult issues.

Mr Gardiner:

Thank you.

Mr Brady:

Thanks for the presentation, Minister, and for being here today. At my time of life, I should feel reassured, John, about your plans for care of the elderly. However, I may have to go into more detail.

I am going to be absolutely parochial. Yesterday, Minister, I asked you a question about Daisy Hill Hospital. You talked about a hospital not necessarily being the nearest one but the most appropriate one. I am sure that everyone knows that there has been a lot of speculation since your statement yesterday, and there has also been a lot of what might be considered scaremongering. People want reassurance from you, Minister, John and Andrew that no decisions have been taken.

I spent quite a bit of time reading through the report last night, and I concentrated on the section that deals with acute care. When I read the criteria, and so on, Daisy Hill ticks all the boxes. For instance, when the Committee visited Daisy Hill last week, we saw examples of telemedicine, which you have spoken about quite a lot. It is extremely innovative. There is a facility for GPs to admit patients directly. There is a high-tech state-of-the-art scanner in the new A&E facility and a high-dependency baby unit. There are a number of dedicated and highly qualified staff to whom we had a chance to talk. I think that a new A&E consultant is starting in January. Everything is up and running. It is a cross-border facility: approximately 3,500 people from the South went through the A&E department last year. In total, there were 36,000 patients from the South. At present, six places in the renal unit are set aside for people from north Louth. Daisy Hill seems to tick all the boxes, and there is potential for growth.

I am really asking for a reassurance that no decisions have been taken. As you can imagine, there is a lot of speculation; I know that from talking to people in my constituency last night. Fears were expressed that it is a done deal, and people want reassurance. You talk about resilience, sustainability and patient safety, and Daisy Hill more than qualifies on those issues. A&E waiting times and other indices are good.

Mr Wells:
You have been talking to the ‘Newry Reporter’.

Mr Brady:
Not necessarily, Jim. To be perfectly honest, you probably get more coverage in the ‘Newry Reporter’ than I do. People want reassurance at this point because there is a long way to go, but we do not want initial speculation and scaremongering.

Mr Poots:
I want to do this in a very clear and honest way. I do not want it to be seen as too clever by half.

John will briefly set out the parameters of what is expected of an acute hospital, the necessity for consultants and anaesthetists, and so on. I will then bring a bit of the political angle to it.

Mr Compton:
I will answer your question directly: there is no done deal about any facility in Northern Ireland at this time. The report is explicit in that it did not do that. That was one thing; we had to go back to the Minister to ask him whether he was happy for us to respond in a slightly different way to the original terms of reference, which asked us to comment on each unit. We said that we did not think that that was the right approach. The right approach is to address what should be present in a major acute situation and then talk to local arrangements about how that is applied and how it works, and then come to a proper and responsible solution.

The report also tries to recognise the fact that we can have advice and best practice from everywhere in the world, but it has to fit in Northern Ireland. This is Northern Ireland; it is not anywhere else. The report acknowledges that. In parts of GB — for example, north-east Scotland, south-west England or central city areas — with populations of 1·8 million people, there will be only four major acute hospitals. We are acutely aware of the fact that Northern Ireland has a different tradition and background, which is why we have come to the arrangement of major acute services on five to seven sites. Local ownership is very important, so there would be local discussions. Health and social care must not detach itself from a population that uses and is very loyal to the service and wants to be interested and engaged in it.

Mr Poots:

The difficulty will be the ability of some facilities to attract anaesthetists, consultants, and so forth. That will be a challenge. In fairness to Daisy Hill, the chief executive of the Southern Health and Social Care Trust is keen for the hospital to be sustained in its current form, which is a good starting point. In a bigger future model, the hospital, as it currently exists, would not be sustainable, so it will need to be expanded or the service will contract from it. I have made that very clear pitch. Anyone can see where the trajectory lies. More people must be drawn into Daisy Hill. Northern Ireland does not have the numbers, so it is a matter of people from north Louth and Monaghan using the service. That is absolutely reasonable.

The Chairperson:

That has been happening for years.

However, back to my question: NIMDTA has to sign off on local plans, which affects recruitment and other issues. If a local solution is devised, checks and balances should be built into it to ensure that it does not proceed if that is the will of the people making those decisions.

Mr Poots:

There are no immediate pressures. Time is on our side to get the solution that people are looking for, which is to ensure that facilities do not simply stay the same but are enhanced. There is a lot of time to work up a solution.

The Chairperson:

So there will be a commitment to recruitment across the board. It will not be a case of Belfast getting the first pick, with the remainder getting what is left.

Mr Poots:

Let us put it like this: 2,200 babies are currently delivered in Daisy Hill. We could not ask another hospital to do that without giving it a significant capital injection.

The Chairperson:

There are other elements to that issue.

Mr Poots:

There is a series of issues. There is no immediate threat to Daisy Hill Hospital for a whole raft of reasons. There is an opportunity to ensure that more people use Daisy Hill Hospital, which will help to ensure that it maintains its current services.

The Chairperson:

I will try to keep this session as tight as I can. Mickey, I know that you wanted to ask about the Commissioner for Older People, and I will bring you back at the end if there is time.

Ms Lewis:

I thank the Minister and the panel for giving their time to come here today. I welcome the report. I do not think that there is anyone who does not agree that major changes are needed in the health system. How will you bring GPs together into 17 groups? How will you liaise with the British Medical Association (BMA) and the Royal College of General Practitioners?

Mr Compton:

A lot of work is already under way, and the Committee had an evidence session recently about primary care partnerships. What we refer to as integrated care partnerships is the same thing, but it allows other disciplines to be involved. We have 17 such arrangements in the Province. Interestingly, just to reflect on the local debate, there has been no one size fits all. We have asked locally about the best way to do it. For example, in the west, it was thought that it could be done best with two groupings, whereas Belfast wanted four groupings. We did not have particular problems with that. It was built up locally and is about local ownership of a solution.

In my discussions with all the GP representatives, I have had nothing but very strong support for the model. Clearly, they are concerned about the ability to discharge their duties and that the financial modelling, which will see a transfer of £21 million over time into family practitioner services in primary care, is designed to provide that reassurance. I have heard nothing from any member of the GP fraternity that is other than supportive for our direction.

Mr McCarthy:

Thank you for the report. There are some good things, and there are also some not so good things that could be very worrying. I will follow on from Pam’s comments. Will rural GPs be expected to close their practices and join with a larger practice, which would mean that patients would have to travel further?

Mr Compton:

No, not at all. The model is about GPs working together as networks. It does not mean that GPs have to change their buildings. If GPs decided that it was right to change a building for a better outcome, that would be a matter for debate and discussion. However, there is no plan to dismantle what people recognise as the 350-plus general practitioner surgeries. We are talking about those GPs working in a different way so that they have more evidence and can look at the way in which they are treating illnesses, such as long-term conditions, in the most responsive way and with the minimum variation in treatment, which will lead to better outcomes for individuals.

Mr McCarthy:

You mentioned your review of respite care. What are the pathways and structures for the development of respite services? Will it be statutory or private, and will users be asked for their input?

Mr Compton:

When we spoke to people, we were told very firmly about the need for respite care. Of course, there is a spectrum of respite care. The care can range from one or two hours to allow people to leave their home to do something to a week-long break. Respite care cannot be designed to a one-size-fits-all arrangement. However, it will clearly have to be a local decision involving families and carers. The inclusion of carers in the review, and making a strong statement about them, recognises their central importance.

Mr McCarthy:

Proposal 46 is about the development of a new Headstart. Is that a replacement for Home-Start, which does an excellent job? We are always asking for it to continue.

Mr Compton:

No. We have a lot of things called Sure Start and Home-Start, and a lot of local projects grouped together. The objective is to get that into one coherent strategy so that everybody is pointing in the one direction. The idea is that, from pregnancy to the age of five, we put a huge effort into making sure that youngsters are developed in such a way that they can benefit from the education system and that early problems and difficulties are quickly diagnosed and sorted out. There is very clear evidence that, if that is done by the age of five, the use of services in later years is reduced. It is not so much about reducing services but about producing healthier kids with better social well-being.

Mr McCarthy:

I agree 100% with that, but there is a fear that people using Home-Start are losing out and that it will have to close. Can you guarantee the Committee that that will not happen and that they will be brought in immediately?

Mr Compton:

We can look at the £83 million transfer of funding that we mentioned. From memory, £41 million will go into community services. Child health and family and childcare are part of community services. We want to put transitional money into that in the first instance, and subsequently money will come out of the system as the system starts to change.

Past reviews were criticised because they told people about changes but not the other side of changes. In this review, we specifically wanted to say: here are the changes, here is the other side of the changes, and here is what will happen as a consequence of the changes.

The Chairperson:

I do not know whether you have seen 'The Connected Baby' by Dr Suzanne Zeedyk. You need to watch that DVD and speak to her if you are developing services for children between nought and five.

Kieran, how long is that list? I might let you back in at the end as well.

Mr McCarthy:

I want to carry on from Sam's question about the residential homes that you want to close. We have been given a commitment on several occasions in this room that a number of special patients in Muckamore will be given a guarantee that they can remain there for as long as they live, because that is what they and their relatives want. I am talking about a very small number of patients. Can you give us that commitment again today?

Mr Compton:

As with all issues in which we are handling very difficult individual sets of circumstances in long-stay institutions or residential care, solutions have to be tailored for individuals and individual groups. There will always be the ability to tailor those individual solutions. The review is not about running around wholesale getting people to pack their bags and move. It is about a sensible direction over a period of time. If there are particular issues with which we have to deal, of course they will be dealt with in their individual circumstances.

Mr McCarthy:

That is reassuring for that small number of people.

Mr Poots:

There will always be trauma in moving people from long-term institutions. However, I can assure you that there are still many people in Muckamore who should not be there. There are better care models for those people.

I want to touch on the issue of children, which currently crosses a number of Departments. I think that we can do much better than we do at present. Whether one Department takes on more responsibilities for children or we have a better integrated way to bring Departments together to work more closely on delivery, we can do more, and we can do better. If we have early interventions, I am confident that we will deliver far better outcomes for young families, particularly vulnerable families.

The Chairperson:

If we get it right initially for our most vulnerable people, there will be less pressure on the Department of Education, the Department for Employment and Learning, the Department for Social Development and the justice system.

Mr Poots:

The Department of Culture, Arts and Leisure (DCAL) and the Office of the First Minister and deputy First Minister (OFMDFM) also have roles to play.

The Chairperson:

Kieran, if you need any more information, I will let you in again at the end. I will take questions from Jim, John, Gordon, Paula, Mark and Mickey. Jim, you are next.

Mr Wells:

Sounds like a ’60s pop group.

You had an excellent interview this morning, John, on ‘The Stephen Nolan Show’. In fact, I felt sorry for him at the end — I did not think that I would ever have to say that. You explained very well many of the points that I would have raised this afternoon, and I will listen to the interview again on iPlayer to go over your points.

I have a couple of questions. You said that, if hospitals can prove themselves to be safe, resilient and sustainable, they pass the test to continue with their present range of services. I am absolutely certain that the chief executives of the health and social care trusts are, from yesterday, starting out on a programme to prove that all their hospitals are safe, resilient and sustainable. What happens if they all deliver the goods and all come up with a programme that indicates that they satisfy those tests? How do you then reach your target of five to seven hospitals with A&E departments?

Mr Compton:

Since it has not been possible to produce safe, sustainable hospitals in the current model of 10, I would be very surprised if people were able to create an environment in which the difficulties that we have today were overcome. If the difficulties that we have today in many of our facilities were as easily overcome as that, I would expect solutions to have been found some time ago.

It is quite clear that we have difficulties — with the volume of activity in some hospitals and its effect on quality of outcomes, in sustaining medical cover and medical staff and in working with regulatory bodies such as the Northern Ireland Medical and Dental Training Agency (NIMDTA). By the way, NIMDTA is not being given a veto. The review is quite clear that NIMDTA should be much more integrated in how it works in the hospital sector and should not sit outside the sector creating difficulties.

Given all those issues, I would be very surprised if we could sort that out. Take, for example, the management of coronary care and cardiac catheterisation in particular: I cannot see how we could have 10 24/7 cardiac catheter labs running across Northern Ireland. People are much more likely to have a better outcome and survive longer if they go through cardiac catheterisation. It is simply not organisable in that way.

Mr Wells:

The chief executive of the Southern Trust is already committed to both her hospitals reaching those standards. What happens if they enter negotiations and track a large number of patients from the Republic to give you the quantum that you need to sustain all those services in Daisy Hill? Is that an important aspect that could lead to more hospitals being retained.

Mr Compton:

Of course that is an important aspect, which is why the review team went to Dublin on a couple of occasions to talk to colleagues in the Southern jurisdiction. The words at the bottom of page 108 of the report were formally agreed with the Southern jurisdiction; they are not accidental words written by the review team. We were very clear that we wanted those words to be precise and understood. My understanding is that, at ministerial level, those words are fairly understood and agreed.

It is common sense for both jurisdictions to talk to each other. It is nothing to do with politics; it is to do with common sense. If we can assist colleagues in the south Down area through to the Cooley peninsula, which will bring more activity to the Newry area and to the hospital, there will be a better outcome for patients. It is the same for the south-west hospital, which clearly indicated that it wants different arrangements, and for Derry, which indicated that it wants different arrangements for cancer services. That makes absolute common sense for patients and for better outcomes. We have no difficulty whatsoever with that. The reason why we spent so much time on that area was to achieve a practical outworking for both jurisdictions.

Mr Poots:

Coming further inland, Craigavon Area Hospital has a cath lab that does not operate 24/7. We could provide cath lab facilities for people who live well into the South. Even for people who live a couple of hours away, it would be a reasonable service to supply and would enable Craigavon to move up to a 24/7 system, which would greatly enhance the services to the west of the Province.

Mr Wells:

I have one small technical point. For some reason, your interviewer on radio this morning got very touchy when you talked about obesity; I cannot understand why. The report mentions some form of fat tax.

Mr Compton:

That is how it was portrayed; that term is not in the report.

Mr Wells:

I understand that you are trying to discourage people eating unhealthy foods, which is a good idea. Can we do that legally?

Mr Compton:

That is, again, why the wording in the report is very careful; we know that this is between a devolved and a national issue, so there is no word of a tax or anything like that. The report asks for an exploration about pricing, which is reasonable. That was asked for because we know that there is a direct correlation between pricing and consumption. From our point of view as a review team, given that we know that there is evidence on the correlation between pricing and consumption, it does not seem unreasonable to ask colleagues and those in the Assembly who are working on the issue to reflect on that.

The Chairperson:

Jim is asking on behalf of he who shall not named: "KFC: yes or no?" That was what was asked on the radio this morning.

Mr Poots:

If there is a tax on crisps, I am going to make a plea of mitigation for Tayto cheese and onion not to be included. *[Laughter.]*

Dr Andrew McCormick (Department of Health, Social Services and Public Safety):

The Executive have discretion to introduce taxes that are not the same as national taxes. We cannot change VAT or income tax, but there is some scope for novel taxation powers.

Mr McCallister:

The national Government have been toying with the idea of a plastic bags tax. Do you think that the discussions with the local public about A&Es such as those at Daisy Hill or the Causeway Hospital developing into other models of care? Is that where the issue is likely to go? Jim and I are South Down representatives. That is a neighbouring constituency of Newry and Armagh, where Daisy Hill is located. It is my nearest hospital. How do you bring people in, engage with them and have that debate? Making changes such as that is a very emotive subject.

Mr Compton:

We went into some detail about the definition of emergencies, from regional trauma, which people understand, to blue-light trauma, which people also understand — it is a state of collapse or something like that — to urgent care and minor injuries. Any population needs access to all those services. The difficulty is that we have a one-size-fits-all service. People go to one area to get all those things done at one point in time. That causes some of the difficulties with seeing people quickly and properly. We need to look at the component parts of emergency services. We indicate in the report that, if you use what is known as the Manchester triage system, which is a straightforward gradation of people turning up, about 50% of people who come in would not qualify as emergency cases.

It is important not to turn people away. They should be given information so that they can go to the correct place, and we must ensure that an alternative is in place. That is why the review is joined up and includes integrated care partnerships, greater involvement of out-of-hours and general practice, and federations of GPs working together. There are things that people should go there for and get sorted out. Sometimes, people do not go because they feel frustrated that they are unable to get the service that they require. The review tries to join that up. It should not be read as talking about a single A&E; it is about trying to join up all of that.

Mr McCallister:
There are some very laudable targets, such as increasing the number of consultants and increasing throughput and access to all our health services. Will that not be tremendously difficult if £83 million is taken from the acute side to put into the community side over a five-year period?

Mr Compton:
Any change, of course, is a challenge. The difficulty is that, in many instances, we probably overuse our hospitals for the wrong things. It is about getting the proper alternative to such overuse to allow money to be taken from hospitals. It is not about denying someone who needs hospital admission or access to treatments or services. Many people with long-term conditions frequently find themselves in hospitals. Perhaps they will have multiple admissions in a year. If community services were better organised, the number of times that they may have to go to hospital could be restricted. That is not because you want to restrict hospital admission, but because people would not need it, and their outcomes would be better. If that were to be the case, the ability and need for hospital work is reduced. Hospital work would concentrate on what it wants to do, which is to deal with the people who are most ill and most in need of support and treatment in the correct environment.

Mr McCallister:

The Minister made a point about working better together with Departments. I do not think that there will be any argument against that. In fact, we are very supportive of that. It is right that you want to move as many people as possible out of institutions such as Muckamore, but the difficulty is that we do not have the right support mechanisms. Supported living could be used for some conditions, but there is a dependence on other Departments doing their bit first. It is about how that is made to work.

The same applies to the Headstart strategy. I very much welcome it, but we have different strategies, and we need to tie them all together. Yesterday, in answer to a question on your statement, you quite rightly talked about that. As well as you as a Minister, others have a responsibility for health. The Chair mentioned the Suzanne Zeedyk DVD, and you are tying in issues such as that. OFMDFM has a childcare strategy, and the Department of Education has a nought-to-six strategy. How are we tying all those bits of policy together? Do you see this as the overarching strategy? Which Department will take responsibility to get the outcomes that you and the Chair mentioned? Will it be the Department of Education, the Department for Employment and Learning or the Department of Justice? If we get it right, we could make a huge impact, but someone has to take the lead and get other Departments involved.

Mr Poots:

Over the past six months, there has been engagement, which I hope will rise in significance. We spend a reasonable amount of money on it, and we could get better value and deliver better outcomes by working more closely together. I have not detected any reluctance on the part of other Ministers. I do not think that Andrew has detected any reluctance on the part of other senior civil servants. It is a matter of how we approach the issue, put our heads together, remove the unnecessary silo walls and work as one Government for the people of Northern Ireland to ensure that we deliver a better service. We recognise the fact that more can be done; let us get our heads around how we do it.

The Chairperson:

With the Department of Health taking the lead.

Mr Poots:

I do not want to say that, because the Department of Education may think that it should take the lead. I am not sure that it does, but we need to engage in a positive way. The Health Department is not looking to grab it all: it has a fair bit to do, and it will do it if other Departments wish it to. This is not a grab to bring more powers into the Health Department.

The Chairperson:

I do not think that anyone is suggesting that you would do that. We had a similar conversation this morning at a Committee for Employment and Learning meeting about people not in education, employment and training (NEETs). We agreed that it is a cross-departmental issue, but, very clearly, the Department for Employment and Learning is in the lead, needs to give leadership and drive the issue from within the Department. We do not suggest that you are grabbing powers, Minister.

Mr Poots:

I would be happy to do it, but on the basis of agreement with our other colleagues. Let us just see exactly where they are on it.

Mr McCallister:

Like the Chair, I am nervous that no Department is leading on the issue. It is always someone else’s job. I want someone to lead on it.

Mr Dunne:

I thank the Minister and the panel for coming before us. Is it fair to say that all the consultation before the publication of the report has somewhat reduced its impact? How do you intend to continue that consultation?

My second point — it has been raised previously — concerns staff. Staff are our most valuable resource, and the report has raised concerns among staff throughout the health sector. We need staff co-operation to implement the report’s proposals. How will you engage further with staff to reassure them that the report represents the best way forward? We are all concerned about the morale of front-line staff. A proportion of staff feels undervalued, and many feel that they are working under excessive stress. Those issues need to be considered, and I trust that you will look at them in more detail.

A further concern is the future of the Belfast hospitals, which has been mentioned. As I understand it, the proposal is to move towards one hospital. The Royal Victoria, the Mater and Belfast City hospitals will all effectively become one hospital — one hospital authority is, I suppose, the proper term. Will that result in a reduction in A&E services or a major review of provision in Belfast?

Mr Poots:

I can deal with that. This morning, I engaged with and offered to do workshops with the BMA, and to sit down with GPs, one to one in as many circumstances as possible, during such workshops. I am engaging with the Royal College of Nursing tomorrow. That engagement work will continue. As I said, we would like to bring a debate to the Floor of the House so that the public debate does not go away and the public remain engaged. It is very important that we seek to draw down the public's views. Perhaps we will not always agree with the public's suggestions. We have to demonstrate leadership and show that, clinically, we can get much better outcomes and that this is the right mode of direction. Sometimes, there will be loud voices, but those voices may not be speaking facts. There is work to be done, but we need to engage strongly with the public and hear what they have to say. We intend to continue to do that.

During the review process, John has always said there was £4·3 billion in the budget at the start, and that at the conclusion there was £4·6 billion in the budget. We are not looking at wholesale cuts in staff. A reorganisation will take place. As a consequence of the funding, there will be some reduction in staff, but it will not be massive. We have avoided compulsory redundancies at this point.

Let us look at issues such as residential homes. What are we doing with residential homes? We are not throwing people out of those homes. At this point, we are identifying that, given the number of people whom we anticipate coming into residential homes, we will need considerably fewer. Where they are in place, they will probably be more for respite care than anything else. So what happens to the staff who work in residential homes? The reason we require fewer residential homes is that we will have more packages for people in their own homes. The people who provide care in residential homes can easily transfer to providing care in people's own homes in the domiciliary sector. That will not be hugely painful, but it will be a change for those types of workers.

There will be other changes. Some services will become more specialised at fewer sites, and so forth, but it is more about reconfiguration than redundancy.

Dr McCormick:

I want to come in on Belfast A&E departments and consultation. The follow-up to the report is the development of detailed specific plans for different issues. Where there is a need for a significant change, the standard process of formal public consultation will be required. As you point out, one example that is actually ahead of the review process is what happens with A&E configuration in Belfast. A temporary change has been made. The fact that a temporary change was needed means that there is a need to consider what the best permanent solution would be. I had a meeting with representatives of the Belfast Health and Social Care Trust this morning, and work is in hand to develop proposals for public consultation in the new year about how that is settled on a permanent basis. That will take its course within the principles set out in the report, but, case by case, as those arise, there will be proper processes of engagement and follow-up public consultation.

Mr Poots:

In August, September and October of this year, 12-hour waits for A&E services in the three Belfast hospitals ranged from 63 in one month to 89 in another month. In November, at the two-hospital site, the total was three. That is a demonstration. Doctors tell us that they are being spread too thinly, their skills and services are being compromised, and junior doctors are being left to make significant decisions and are finding it difficult to come to those decisions. Where registrars and consultants are in place, there will be better outcomes and decision-making. There were considerably better outcomes in November than in the previous three months. People need to reflect on that and consider why it is the case.

The Chairperson:

There have not been very many 12-hour waits in the Southern Trust area over the past years. I ask that you bear that in mind.

Ms P Bradley:

I would be lying if I said that I had read the report from cover to cover, but I have read the highlights. I agree with the majority of what I have read. I think that if you took this document to many health professionals they would say that it states what they have been saying for years; that we should be doing X, Y or Z. When implemented, it will make such a difference, especially to social care. I am very happy to see such an emphasis on social care, as I have said time and time again that it is the cornerstone.

The first of my two questions is slightly parochial and, in that sense, is a bit like Mickey's question. North Belfast is serviced by the Belfast Trust and the Northern Trust. There is the Mater Hospital, which is a blue-light facility, and Whiteabbey Hospital, which is not, because it was taken off us under the previous Administration. Have you any plans for the Belfast area, and will you clarify the difference between acute hospital networks rather than acute hospitals;

The other point that I want to bring up is technology in hospitals. In the hospital where I worked, we had to log on to three separate computer systems just to complete a front-sheet referral form, which is one sheet of information. Also, at the end of the patient discharge process, information had to be input into three computer systems. Staff are extremely busy with having so much to do, and yet they are expected to use that many systems.

Also, in my area, with there being two separate trusts, someone taken in a blue-light vehicle to the Mater Hospital for surgery might, a couple of months later, be transported in another blue-light vehicle to Antrim Area Hospital for more surgery, intensive care, or whatever. Again, that means two different computer systems with two totally separate sets of notes. That often means that a surgeon in one hospital cannot get the notes from another hospital. I have heard of families getting in their cars and driving at speed to pick up notes from another hospital.

The current technology is not workable. In no way does it benefit the patient, and it costs a great deal of money to maintain the computer systems that I mentioned, and there are many more besides: for GPs, hospital medics, pharmacies, and so on. Not only would streamlining make major efficiencies, it might go a long way to reducing stays in hospital and, ultimately, the number of patient deaths.

Mr Compton:

I will pick up on two points, the first of which was the argument about whether adjacent populations should talk to each other about how they organise services. The answer is yes, they should, and the report is quite clear about that. Although we expect population planning to take on the core activity for that population, those populations are, no matter how you draw them, somewhat artificial. There needs to be a concept and a discussion with the adjacent population. So we expect that, when the local commissioning plans for the Belfast and Northern Trust areas come back, there will be interplay on the boundary issues, just as we might expect between the Northern and Western Trust areas, the Southern and Western Trust areas, or wherever. It is just common sense for that to take place.

Part of this is about becoming a bit more efficient. There is a lot in the document about technology. At public meetings that I went to, I heard profound concerns about the backwardness of our technology when people compared their experience of the health system with the rest of their lives. One of the key issues for us is to sort out the technology.

In the document, we highlight some of the issues that we think are quite important, starting with having a forum in which we can talk to the industry so that we understand what is happening there and they understand what our needs are. Then, at a certain point, we will be talking a similar language before getting into procurement. We are looking at having a single system and at better data warehousing of information that can be properly accessed in a way that does not breach an individual’s confidentiality but enhances his or her outcome because the information is available. That concept percolates all the way through the report. If we want to have a modern, effective health system, underpinning that will have to be a much more modern and effective technological system.

Dr McCormick:

Page 120 of the report specifically mentions the electronic care records. Those are being piloted and are ready to roll out in order to deal with exactly your point about the commonality of information and making the same information available to clinicians wherever they are.

Mr Durkan:

I apologise for being late. You might think that a pattern was beginning to emerge, given that I was late for the Minister's statement yesterday.

The Chairperson:

I was sympathetic, because the wrong information on the annunciator caused some confusion yesterday. Really and truly, for that reason, Members who were late should not have been left to the end of questions to the Minister.

Mr Poots:

We were very sympathetic, too.

Mr Durkan:

Being left to the end meant that we knew what questions the Minister did not want to be asked because they had not already been put to him.

I very much welcome the report and congratulate John and his team on its compilation and publication. It is styled as a road map for the future, but I see it more as a compass. It points us in the right direction without necessarily giving us the specifics of how we will get there. I certainly like the destination, and the report crystallises a lot of the ideas, which have been espoused by this Committee and by Health Committees long before I came to the Assembly, on a shift of focus from secondary and clinical care to primary and social care.

Other members mentioned the report’s greater emphasis on preventative measures and its nod to cross-border co-operation. I have always been a big fan of integrated care partnerships, and I am glad that the need for transitional funding for that is identified and, indeed, costed. I also raised that issue previously. It is vital that no vacuums in care are created as we move from one model to another. Are you confident that the funding is forthcoming and that it will be enough?

The lack of specifics in the report causes the public concern. Reference is made to an expanded role for community pharmacy in delivering the new model. People in that service will be curious about whether that will involve enhanced funding to enable them to play the role envisaged for them in that delivery. The report is not specific in identifying where and when the reduction of acute services will take place. I appreciate that a lot more work is to be done on that.

Gordon raised the vital matter of staff, and I was able to ask the Minister a question on that yesterday. I appreciated the Minister's answer yesterday that the report is about the health service rather than health servants. However, it is important to note the importance of the morale of health servants, because, without happy health servants, there will be no health service.

Minister, you referred to the budget moving from £4·3 billion to £4·6 billion. In real terms, given the ageing population and increase in demand, is that an enhancement —

Mr Poots:

That is why the report was necessary.

Mr Durkan:

— or a reduction? What will be the next steps in the process? I mentioned the staff, and I appreciate that you spoke to the BMA this morning. In an earlier evidence session, I emphasised the importance of including the unions in the consultation period. That should be done as a matter of urgency.

Mr Poots:

I will deal with the finance and pass the other issues on to John. We started off with a budget of £4·3 billion. That is moving to £4·6 billion, which is an increase of 8%. That would probably not keep up with inflation over the period, although there has, for a couple of years, been a freeze in the pay of staff earning over £21,000, which helps. However, our problem is that, if we were to carry on doing things the same way as we do currently, we would, ultimately, have to cut services. The costs associated with demand are rising by about 4% each year. That is largely to do with the population getting older.

The budget increase is 8%, but if you consider that our costs are rising by 16% and then add on the cost of inflation, you can see that there is a pinch point, which can be met only by extending waiting times for services. That is why, at an early point, we identified that we needed radically to reform how we provide care. I asked the panel to take on the report on the basis of delivering better outcomes. The members of the panel were aware that this was the budgetary envelope that we had to live within. In spite of not getting the rise that we would like to get — I appreciate that other Departments in Northern Ireland suffered far more than mine in the Budget rounds and have a great degree of sympathy with a lot of my ministerial colleagues — we believe that we can get better outcomes from the budget that we have if we use that money more wisely and spend it better. That is how we ended up with 'Transforming Your Care', and John will explain how it will work.

Mr Compton:

On the issue of morale, it is worth observing that we met many, many, many staff who work in the system, not one of whom wanted that system to remain in its current form. They clearly knew that something had to give. That is why we said early in the review that we were failing staff by not making reforms. One of the compelling arguments for change is that asking staff to work in the current pattern and manner is failing them, and they know that. There is an appetite and enthusiasm for making the change.

As for whether the shift of £83 million and transitional funding of £70 million are enough, no restriction was placed on what the review panel could or could not do. When we looked at this, we had to do so with a degree of realism, a degree of achievability and a degree of deliverability, and we felt that the numbers specified in the review were just that: realistic and deliverable. If we go ahead on the basis of those figures, some of the shifts into areas such as family practitioner services and community care will be quite significant in proportion to what is currently spent. The shift into community care, for example, lifts its funding up by around 9%. Those are quite large numbers, so there is a real opportunity for something different.

There will always be a debate about whether there is enough money. I will finish talking about the money issue by saying what I said at the public meetings: we are in a much better place to talk about what should or should not be invested in health and to provide advice if the model that we have is the right shape and structure. It is very difficult when people just turn round to you and say, “Put your own house in order first.” This is, if you like, putting the house in order and giving you a more coherent argument. The panel was not constrained, and we said what we said.

Mr Durkan:

Thank you, John. I acknowledge your recognition of the importance of staff during the consultation phase, but they have been in a state of perpetual change for so long. That is why it is so important that we get this right and arrive at the destination without running out of petrol on the way.

Mr Poots:

I believe that we have enough money in the system to deal with people's needs but not enough to deal with people's abuse of it. For example, four times more people in Northern Ireland have consultations in GP surgeries than in the Republic of Ireland. Our figure for that is also 25% higher than in other parts of the UK. We have more people coming to A&E units than should be the case. Work in Craigavon identified that at least one third of the cases coming through the doors of A&E should not have been doing so. Some 25% of people who call ambulances should not do so. Then, we have others who think that they can eat, drink or smoke themselves into bad health and that the health service is some garage repair shop that will put them right. Very often, it is impossible to put them right.

The public health agenda is critical. Around Europe, the spend on public health is around 3%; we spend less. It is important that we get the message out to people that they are responsible in the first instance for their own health and that we are there to meet their needs when something goes wrong. Far too many people engage in activities that lead to their coming to hospital absolutely unnecessarily.

The Chairperson:

Minister, I know that we are tight for time, but I will let Mickey in, as I promised, and then Kieran will ask one question only.

Mr Brady:

Maybe we should all follow Jim's lead and become vegetarians.

Mr Wells:

Hear, hear.

Mr Poots:

His waistline is too large. *[Laughter.]* He does not meet our requirements.

Mr Brady:

You talked about a holistic and consistent approach to the assessment of older people's needs and an equitable range of services. We have the advent of a Commissioner for Older People, Claire Keatinge. That position seems like a logical conduit for the groups or voluntary organisations such as Age NI and the Age Sector Platform that deal with older people, or "senior citizens", as Sam would have them termed. Rather than the commissioner being on the outside, will she become an integral part of that kind of project?

Mr Compton:

The answer to that is yes, because it would not work otherwise.

Mr McCarthy:

John, you talked about meeting a lot of staff on your rounds before you produced the report. As I understand it, the shared services document was not out and about at that time. I do not know about other members, but I am hearing concerns from many constituents about what is contained in that document. In other words, people who live in Newtownards are concerned about having to travel to Omagh or Derry. Have you an answer to that?

Mr Poots:

Through shared services, 500 jobs will become 400. Quite a number of people who currently work in personnel, for example, will find that their job moving perhaps 60 or 70 miles away. However, training will be offered to enable those individuals to go to a closer shared services office. For example, people in Newry who previously specialised in finance would not be expected to travel to Ballymena, because jobs would be available in Armagh for those individuals if they retrained in personnel. There will be opportunities for retraining, and there will also be opportunities for the trusts to absorb a number of those staff. It will not lead to wholesale compulsory redundancies. I cannot rule out there being some, but there will be very few. When it comes to elections and talking about health, all of you say that we need to cut management and administration, so do not complain when it happens.

Mr McCarthy:

I thought that no jobs would be lost, but if that is the case, jobs will be lost. You are contradicting yourself at the final hurdle. John, you said this morning on 'The Stephen Nolan Show' that no jobs would be lost.

The Chairperson:

I am glad that you asked that question, Kieran. There is a big shift away from the west as well. We talked about it last week and are very concerned, but that is not for today.

Mr Poots:

We have put something into Omagh, whereas others took services away.

Mr Dunne:

Is there not a new hospital being built in Enniskillen?

The Chairperson:

There is, yes.

Minister, quite a few times, you mentioned people smoking, drinking and eating themselves into ill health or to death. We could be forgiven for thinking that you might be having a pop at people in socially deprived areas. I remember what you said in the House about the upper Finaghy bus route. The fact is that a lot of people who are professional or consider themselves to be middle class suffer from high blood pressure and stress. Ill health is not just caused by the lifestyle choices of the poor and not so famous; we all have medical conditions as a result of how we live. There are times when all of the focus and attention is on people from socially deprived areas, and that is not fair. You might want to bear that in mind.

You talked about cardiac catheterisation. We have seen services being reconfigured. I know that some people go to the minor injuries unit when they should go down the road to the A&E unit in Craigavon. I do not know whether anybody who goes to A&E in Craigavon is told that they can either sit there for five hours or travel half an hour down the road to Dungannon and be seen in the minor injuries unit. I do not know whether that is said at the point of triage in Craigavon, but it would certainly make sense.

There has been quite a focus on Daisy Hill Hospital. In defence of the Northern Trust and the Causeway Hospital, services like cardiac catheterisation could remain. I hope that this is not an all-or-nothing scenario and that you can work with local trusts and local commissioning groups to decide what is needed. I am conscious of the geography surrounding the Causeway Hospital and the radius from which people look to it for services such as cardiac catheterisation. The fact is that people are a long way away from the next hospital that offers such services. What happens when someone in Draperstown, for example, needs a cardiac ambulance? Is there a plan to retain services where their provision is of high quality? Is there any attempt to dilute this reconfiguration?

Mr Compton:

I will give you a specific example: look at the work undertaken recently in urology. We now have three centres: Craigavon, Derry and Belfast. That was agreed across the whole of Northern Ireland. Those three inpatient centres support the rest of the hospital network through day cases and outpatient services, and they provide assessments for patients who may have presented with a problem that turned out to be urological. That is the model and the way forward. It responds to the accessibility issue.

The review was very mindful of having to design some direction of travel and a road map that accommodates and fits Northern Ireland. I think that we have done that. That was a very clear objective at the outset, and we made that quite explicit, almost on the front page of the report. In the end, that model has to have legs and be believed in, in Northern Ireland. You cannot just apply something from somewhere else.

There is an important issue of volume in some situations, and there is interplay between the volume of activity and time. All of that will be taken into account in the organisation of the major acute networks across the Province. Clearly, those must be important criteria. Perhaps behind your question is another: is this a recipe to locate everything in Belfast and take away everything outside Belfast? The answer is that it absolutely is not.

The Chairperson:

We accept, for example, that one regional trauma unit is probably a practical solution, but the fear is that some people will, if you like, drop off the edge because they are too far away. Correct me if I am wrong, but I understand that the report acknowledges that some services are too far away for those people, but that that is just tough.

Mr Compton:

Look at the published evidence on the travel time and the outcome — and the outcome is the important issue. What is the best outcome for someone? A lot of work on trauma, for example, has been carried out in Scotland. It shows definitively that travel time is less important — it is not unimportant but less important — than getting to the right place and the right unit that can fix you. What gets you the best outcome is getting to the right place and the right person in the right time. That is one of the principles that governed what we have to say.

Most people will ask, "Why would you drive past that unit to go somewhere else? Surely it would be better to go there. They will do something and then take you somewhere else." In fact, that is often the wrong thing to do.

The Chairperson:

No one on the Committee has said that. In fairness to all members, none say that people should go to the wrong place. We know that going 10 miles down the road can give people a better outcome. We do not disagree with that, John. However, it is important to recognise that travel times make an impact. You have seen the survey that was done in Scotland. Are the people who die on the road, having been worked on in the back of the ambulance and made it halfway down the M1, included in the statistics?

Mr Compton:

Obviously, we will get you all that information if it is helpful. The point that I want to make is that the reason that we came up with the five to seven networks is, in part, to understand accessibility in Northern Ireland and travel times for major and critical issues. It is not just applied as some sort of arithmetic formula, such as 1·8 million people divided by a population by 450,000 equals 4 acute hospitals. That is what would happen in lots of other places. The report takes account of some of the infrastructure and journey-time difficulties in Northern Ireland. That is why the report is explicit about the hospital in the south-west. It is a very direct response to the issue of Northern Ireland. That is a real issue; that is why there is a hospital in the south-west. There is recognition of the rurality and accessibility issues of Northern Ireland and of the road infrastructures. The review has been quite clear about that. I hope that, in the outworkings of the review, people will see that as a fair, balanced and proportionate response.

The Chairperson:

I am conscious that we are a few minutes over time. I thank Andrew, Edwin and John for coming today. It would be helpful to have an update on progress. Will you come back towards the end of January? I agree with Mark that the report lacks specifics. We might be able to dig further into those specifics in the new year. John, you did not answer the question about who is on the forum, and we will need more specific information on that.

I would also like a flavour of the kind of responses that you are getting. I know that there is no formal consultation as such, but, presumably, people will be engaging with you and making their thoughts known. We would appreciate that information as well. We would be especially keen to hear how the trade unions feel about it. A dedicated meeting on that towards the end of January would be helpful.

Mr Poots:

We are always in the hands of the Committee. I draw one small matter to your attention. On 23 November, John Compton and Deirdre Heenan attended the Committee. I noted, in Hansard, that Deirdre Heenan referred to a number of areas in south Down that are about 17 miles from the out-of-hours doctors. The Hansard report incorrectly recorded Ballymoney as one of those areas. I am very disappointed Committee members from that area had not read Hansard and had it corrected it to read Ballyroney. Of course, we are always looking at boundary reviews, and if it wants to go into the Lagan Valley constituency and be properly cared for, we would be very happy to do that.

The Chairperson:

That is very helpful. We wish you all a very happy Christmas, and we will see you in the new year.

NICE National Institute for Health and Care Excellence

NICE guideline

Patient experience in adult NHS services: improving the experience of care for people using adult NHS services

Clinical guideline
Published: 24 February 2012
www.nice.org.uk/guidance/cg138

Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the Yellow Card Scheme.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Contents

This guideline is the basis of QS15.

Overview

This guideline covers the components of a good patient experience. It aims to make sure that all adults using NHS services have the best possible experience of care.

Who is it for?

- Healthcare professionals
- Non-clinical staff who come into contact with patients (for example, receptionists, clerical staff and domestic staff)
- People using adult NHS services and their families and carers

Introduction

Over the past few years, several documents and initiatives have highlighted the importance of the patient's experience and the need to focus on improving these experiences where possible.

Lord Darzi's report High quality care for all (2008) highlighted the importance of the entire patient experience within the NHS, ensuring people are treated with compassion, dignity and respect within a clean, safe and well-managed environment.

The development of the NHS Constitution (2009 to 2010) was one of several recommendations from Lord Darzi's report. The Constitution describes the purpose, principles and values of the NHS and illustrates what staff, patients and the public can expect from the service. Since the Health Act came into force in January 2010, service providers and commissioners of NHS care have had a legal obligation to take the Constitution into account in all their decisions and actions.

The Equality Act 2010 replaces all previous anti-discrimination legislation, and includes a public sector equality duty requiring public bodies to have due regard to the need to eliminate discrimination and to advance equality of opportunity and foster good relations between people who share certain protected characteristics and those who do not. The protected characteristics are age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex and sexual orientation. The Act provides an important legal framework which should improve the experience of all patients using NHS services.

Despite these policy initiatives, there is evidence to suggest that further work is needed to deliver the best possible experience for users of NHS services. The Government signalled in its 2010 White Paper (Equity and excellence: liberating the NHS, Department of Health and Social Care) that more emphasis needs to be placed on improving patients' experience of NHS care.

This guidance is a direct referral from the Department of Health. It focuses on generic patient experiences and is relevant for all people who use adult NHS services in England and Wales. The aim of the guidance is to provide the NHS with clear guidance on the components of a good patient experience. This guidance provides the evidence and the direction for creating sustainable change that will result in an 'NHS cultural shift' towards a truly patient-centred service.

A NICE quality standard on patient experience in adult NHS services has been developed alongside this guidance. NICE quality standards are a set of specific, concise statements and associated measures. They set out aspirational, but achievable, markers of high-quality, cost-effective care. Quality standards are derived from the best available evidence and address three dimensions of quality: clinical effectiveness, patient safety and patient experience.

NICE clinical guidelines are usually shaped around both clinical and economic evidence, and include recommendations concerned with ensuring a good patient experience, with the recognition that such advice should sit alongside evidence of clinical and cost effectiveness. The recommendations in the current guidance have been informed by research evidence, recommendations in previously published NICE clinical guidelines, national survey data and consensus processes that have identified the key elements that are important to patients and how these can be improved to ensure a good experience of care. The guidance draws on multiple evidence and data sources in developing the recommendations.

The recommendations in this guidance are directed primarily at clinical staff, but patient experience is also significantly affected by contacts with non-clinical staff such as receptionists, clerical staff and domestic staff. Services need to ensure that non-clinical staff are adequately trained and supported to engage with patients in ways that enhance the patient experience.

Taken together, the recommendations in this guidance capture the essence of a good patient experience. Their implementation will help to ensure that healthcare services are acceptable and appropriate, and that all people using the NHS have the best possible experience of care.

NICE has also published a guideline on babies, children and young people's experience of healthcare.

1 Guidance

The following guidance is based on the best available evidence. The full guideline gives details of the methods and the evidence used to develop the guidance.

People have the right to be involved in discussions and make informed decisions about their care, as described in making decisions about your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

1.1 Knowing the patient as an individual

Patients value healthcare professionals acknowledging their individuality and the unique way in which each person experiences a condition and its impact on their life. Patients' values, beliefs and circumstances all influence their expectations of, their needs for and their use of services. It is important to recognise that individual patients are living with their condition (or conditions), so the ways in which their family and broader life affect their health and care need to be taken into account.

1.1.1 Develop an understanding of the patient as an individual, including how the condition (or conditions) affects the person, and how the person's circumstances and experiences affect their condition (or conditions) and treatment. See also NICE's guideline on multimorbidity.

1.1.2 Ensure that factors such as physical or learning disabilities, sight, speech or hearing problems and difficulties with reading, understanding or speaking English are addressed so that the patient is able to participate as fully as possible in consultations and care.

1.1.3 Ask the patient about and take into account any factors, such as their domestic, social and work situation and their previous experience of healthcare, that may:

- impact on their health condition (or conditions) **and/or**
- affect their ability or willingness to engage with healthcare services **and/or**
- affect their ability to manage their own care and make decisions about self-management and lifestyle choices.

1.1.4 Listen to and address any health beliefs, concerns and preferences that the patient has, and be aware that these affect how and whether they engage with treatment. Respect their views and offer support if needed to help them engage effectively with healthcare services and participate in self-management as appropriate.

1.1.5 Avoid making assumptions about the patient based on their appearance or other personal characteristics.

1.1.6 Take into account the requirements of the Equality Act 2010 and make sure services are equally accessible to, and supportive of, all people using adult NHS services.

1.1.7 If appropriate, discuss with the patient their need for psychological, social, spiritual and/or financial support. Offer support and information to the patient and/or direct them to sources of support and information. Review their circumstances and need for support regularly.

1.2 Essential requirements of care

Patients have needs other than the treatment of their specific health conditions. There should be recognition of the potential need for psychological and emotional support, as well as of the importance of meeting fundamental needs such as nutrition and pain management. Attention to these fundamental needs applies particularly to inpatient settings, but they should also be addressed in other settings where healthcare is provided.

Respect for the patient

1.2.1 All staff involved in providing NHS services (including chaplains, domestic staff, porters, receptionists and volunteers) should:

- treat patients with respect, kindness, dignity, compassion, understanding, courtesy and honesty
- respect the patient's right to confidentiality
- not discuss the patient in their presence without involving them in the discussion.

1.2.2 Introduce students and anyone not directly involved in the delivery of care before consultations or meetings begin, and let the patient decide if they want them to stay.

Patient concerns

1.2.3 Be prepared to raise and discuss sensitive issues (such as sexual activity, continence or end-of-life care), as these are unlikely to be raised by some patients.

1.2.4 Listen to and discuss any fears or concerns the patient has in a non-judgemental and sensitive manner.

1.2.5 If anxiety disorder or depression is suspected, follow the appropriate stepped-care model recommended in:

- the NICE guideline on generalised anxiety disorder and panic disorder in adults **or**
- the NICE guideline on depression in adults **or**
- the NICE guideline on depression in adults with a chronic physical health problem.

Nutrition, pain management and personal needs

1.2.6 All healthcare professionals directly involved in patient care should receive education and training, relevant to their post, on the importance of:

- providing adequate and appropriate nutrition

- assessing and managing pain.

1.2.7 Ensure that the patient's nutrition and hydration are adequate at all times, if the patient is unable to manage this themselves, by:

- providing regular food and fluid of adequate quantity and quality in an environment conducive to eating
- placing food and drink where the patient can reach them easily
- encouraging and helping the patient to eat and drink if needed
- providing appropriate support, such as modified eating and/or drinking aids.

1.2.8 If a patient is unable to manage their own pain relief:

- do not assume that pain relief is adequate
- ask them regularly about pain
- assess pain using a pain scale if necessary (for example, on a scale of 1 to 10)
- provide pain relief and adjust as needed.

1.2.9 Ensure that the patient's personal needs (for example, relating to continence, personal hygiene and comfort) are regularly reviewed and addressed. Regularly ask patients who are unable to manage their personal needs what help they need. Address their needs at the time of asking and ensure maximum privacy.

Patient independence

1.2.10 Give patients using adult NHS services the support they need to maintain their independence as far as possible.

1.2.11 When patients in hospital are taking medicines for long-term conditions, assess and discuss with them whether they are able and would prefer to manage these medicines themselves.

Consent and capacity

1.2.12 Obtain and document informed consent from the patient, in accordance with:

- in England, Department of Health and Social Care policy and guidance
- in Wales, advice from the Welsh Government.

1.2.13 Assess the patient's capacity to make each decision using the principles in the Mental Capacity Act (2005).

1.3 Tailoring healthcare services for each patient

Patients wish to be seen as an individual within the healthcare system. This requires healthcare professionals to recognise the individual, and for services to be tailored to respond to the needs, preferences and values of the patient. Advice on treatments and care, including risks and benefits, should be individualised as much as possible.

An individualised approach to services

1.3.1 Adopt an individualised approach to healthcare services that is tailored to the patient's needs and circumstances, taking into account their ability to access services, personal preferences and coexisting conditions. Review the patient's needs and circumstances regularly.

1.3.2 Inform the patient about healthcare services and social services (for example, smoking cessation services) that are available locally and nationally. Encourage and support them to access services according to their individual needs and preferences.

1.3.3 Give the patient information about relevant treatment options and services that they are entitled to, even if these are not provided locally.

Patient views and preferences

1.3.4 Hold discussions in a way that encourages the patient to express their personal needs and preferences for care, treatment, management and self-management. Allow adequate time so that discussions do not feel rushed.

1.3.5 Review with the patient at intervals agreed with them:

- their knowledge, understanding and concerns about their condition (or conditions) and treatments
- their view of their need for treatment.

1.3.6 Accept that the patient may have different views from healthcare professionals about the balance of risks, benefits and consequences of treatments.

1.3.7 Accept that the patient has the right to decide not to have a treatment, even if you do not agree with their decision, as long as they have the capacity to make an informed decision (see recommendation 1.2.13) and have been given and understand the information needed to do this.

1.3.8 Respect and support the patient in their choice of treatment, or if they decide to decline treatment.

1.3.9 Ensure that the patient knows that they can ask for a second opinion from a different healthcare professional, and if necessary how they would go about this.

Involvement of family members and carers

1.3.10 Clarify with the patient at the first point of contact whether and how they would like their partner, family members and/or carers to be involved in key decisions about the management of their condition (or conditions). Review this regularly. If the patient agrees, share information with their partner, family members and/or carers.

1.3.11 If the patient cannot indicate their agreement to share information, ensure that family members and/or carers are kept involved and appropriately informed, but be mindful of any potentially sensitive issues and the duty of confidentiality.

Feedback and complaints

1.3.12 Encourage the patient to give feedback about their care. Respond to any feedback given.

1.3.13 If necessary, provide patients with information about complaints procedures and help them to access these.

1.4 Continuity of care and relationships

Continuity and consistency of care and establishing trusting, empathetic and reliable relationships with competent and insightful healthcare professionals is key to patients receiving effective, appropriate care. Relevant information should be shared between professionals and across healthcare boundaries to support high-quality care.

1.4.1 Assess each patient's requirement for continuity of care and how that requirement will be met. This may involve the patient seeing the same healthcare professional throughout a single episode of care, or ensuring continuity within a healthcare team.

1.4.2 For patients who use a number of different services (for example, services in both primary and secondary care, or attending different clinics in a hospital), ensure effective coordination and prioritisation of care to minimise the impact on the patient.

1.4.3 Ensure clear and timely exchange of patient information:

- between healthcare professionals (particularly at the point of any transitions in care)
- between healthcare and social care professionals in line with the Health and Social Care (Safety and Quality) Act 2015.

1.4.4 All healthcare professionals directly involved in a patient's care should introduce themselves to the patient.

1.4.5 Inform the patient about:

- who is responsible for their clinical care and treatment

- the roles and responsibilities of the different members of the healthcare team
- the communication about their care that takes place between members of the healthcare team.

1.4.6 Give the patient (and their family members and/or carers if appropriate) information about what to do and who to contact in different situations, such as 'out of hours' or in an emergency.

1.5 Enabling patients to actively participate in their care

Many patients wish to be active participants in their own healthcare, and to be involved in creating and managing their health strategy and use of services. Self-care and self-management are particularly important for people with long-term conditions.

Communication

1.5.1 Ensure that the environment is conducive to discussion and that the patient's privacy is respected, particularly when discussing sensitive, personal issues.

1.5.2 Maximise patient participation in communication by, for example:

- maintaining eye contact with the patient (if culturally appropriate)
- positioning yourself at the same level as the patient
- ensuring that the patient is appropriately covered (if applicable).

1.5.3 Ask the patient how they wish to be addressed and ensure that their choice is respected and used.

1.5.4 Establish the most effective way of communicating with each patient and explore ways to improve communication. Examples include using pictures, symbols, large print, Braille, different languages, sign language or communications aids, or involving an interpreter, a patient advocate or family members.

1.5.5 Ensure that the accent, use of idiom and dialect of both the patient and the healthcare professionals are taken into account when considering communication needs.

1.5.6 Avoid using jargon. Use words the patient will understand, define unfamiliar words and confirm understanding by asking questions.

1.5.7 Use open-ended questions to encourage discussion.

1.5.8 Summarise information at the end of a consultation and check that the patient has understood the most important information.

1.5.9 Offer the patient copies of letters between healthcare professionals. These should be in a form that is accessible to the patient and if possible use language that they will understand. Answer any questions the patient may have about these.

1.5.10 All staff involved in providing NHS services should have demonstrated competency in relevant communication skills.

Information

1.5.11 Give the patient information, and the support they need to make use of the information, in order to promote their active participation in care and self-management.

1.5.12 Give the patient both oral and written information.

1.5.13 Give the patient information in an accessible format, at the first and subsequent visits. Possible formats include using written information, pictures, symbols, large print, Braille and different languages.

1.5.14 Explore the patient's preferences about the level and type of information they want. Based on this, give the patient (and their family members and/or carers if appropriate) clear, consistent, evidence-based, tailored information throughout all stages of their care. This should include, but not be limited to, information on:

- their condition (or conditions) and any treatment options
- where they will be seen
- who will undertake their care
- expected waiting times for consultations, investigations and treatments.

1.5.15 Ensure that mechanisms are in place to:

- provide information about appointments to patients who require information in non-standard formats
- alert services of any need for interpreters and non-standard formats to be available when patients move between services.

1.5.16 Ask the patient whether they want to be accompanied at consultations by a family member, friend or advocate, and whether they would like to take notes and/or an audio recording of the consultation.

1.5.17 Give the patient (and/or their family members and carers) information to enable them to use any medicines and equipment correctly. Ensure that the patient and their family members and carers feel adequately informed, prepared and supported to use medicines and equipment and to carry out self-care and self-management.

1.5.18 Advise the patient where they might find reliable high-quality information and support after consultations, from sources such as national and local support groups, networks and information services.

1.5.19 Give the patient regular, accurate information about the duration of any delays during episodes of care.

Shared decision making

Recommendations 1.5.20 to 1.5.27 have been replaced by NICE's guideline on shared decision making.

1.5.20 Deleted.

1.5.21 Deleted.

1.5.22 Deleted.

1.5.23 Deleted.

1.5.24 Deleted.

1.5.25 Deleted.

1.5.26 Deleted.

1.5.27 Deleted.

Education programmes

1.5.28 Ensure that patient-education programmes:

- are evidence-based
- have specific aims and learning objectives
- meet the needs of the patient (taking into account cultural, linguistic, cognitive and literacy considerations)
- promote the patient's ability to manage their own health if appropriate.

1.5.29 Give the patient the opportunity to take part in evidence-based educational activities, including self-management programmes, that are available and meet the criteria listed in recommendation 1.5.28.

Finding more information and committee details

You can see everything NICE says on this topic in the NICE Pathway on patient experience in adult NHS services.

To find NICE guidance on related topics, including guidance in development, see the NICE webpage for patient and service user care.

For full details of the evidence and the guideline committee's discussions, see the full guideline. You can also find information about how the guideline was developed, including details of the committee.

NICE has produced tools and resources to help you put this guideline into practice. For general help and advice on putting NICE guidelines into practice, see resources to help you put guidance into practice.

Update information

June 2021: We replaced recommendations 1.5.20 to 1.5.27 on shared decision making with a link to the NICE guideline on shared decision making.

Minor changes since publication

October 2021: We made minor changes to the wording in recommendations 1.1.1, 1.1.3, 1.3.5, 1.3.10 and 1.5.14 to take account of people with more than 1 condition. We also added a cross-reference to NICE's guideline on multimorbidity in recommendation 1.1.1 and to NICE's guideline on babies, children and young people's experience of healthcare in the introduction. We updated the links in recommendation 1.2.12.

June 2021: We removed appendix A on recommendations adapted from published clinical guidelines.

February 2020: We replaced the quality statements in the guideline with a link to the updated NICE quality standard on patient experience in adult NHS services.

October 2015: We updated recommendation 1.4.3 to cite the Health and Social Care Safety and Quality Act 2015.

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